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Quality of Life among Caregivers of Children with Disabilities in the Gaza Strip

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Dedication

Dedicated to my father and mother who suffered from my stubbornness and did nothing but loving and supporting me.

To my Abdullah and Akram who suffered from my absence and less care and only waited until I am available.

To my Mohammed who suffered from my continuous stress and deadly ambition and he only took my hand and kept me patient.

To my sisters who suffered from continuous calls for emergency help and they did nothing but left everything back and ran to me.

To my lovely friends who suffered from my complaints and wailings and they only deeply heard me and filled me with energy.

To every mother who lived with an angel and suffered silently in shadow with no complaint and no one to help.

This effort is dedicated to those surrounding treasures.

Mariam A. Mohanna

Declaration

I certify that this thesis submitted for the degree of master is the result of my own research, except where otherwise acknowledged, and that this thesis or any of its parts has not been submitted for a higher degree to any other university or institution.

Signed:

Mariam A. Mohanna

Date: 11/1/2020

Acknowledgment

Dear respectful teacher, I thank you deeply for your continuous inspiration to do my best, you helped me strive for goals, you gave me guidance, discipline, even friendship, everything in one person; who is Dr. Bassam Abu Hamad. I am so grateful to my precious teachers; Dr. Yehia Abed and Dr. Khitam Abu Hamad because they taught me how and where to look not just taught me what to see.

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Deep thanks to all caregivers who participated in the study because without them this thesis could not be accomplished.

With respect,
Mariam A. Mohanna

Abstract

Background *Caregivers of children with disabilities experience a stressful life with many overwhelming challenges. This study assesses the quality of life of caregivers and highlights the burden of disability they shoulder and who supports them.*

Methods *This study followed a mixed-method cross-sectional approach. The quantitative component was administered on a randomly selected 400 caregivers of children with disabilities interviewed at the household level, with a response rate of 99%. Qualitative data collected through 11 key informant interviews, 6 in-depth individual interviews and 7 focus group discussions with parents of children with disabilities. Quantitative data were analyzed using the SPSS software and the qualitative data were analyzed using the open coding thematic technique. Reliability test was very high.*

Findings *Mostly mothers are the caregivers of children with disability (93%) and in more than 30% of the visited households providing care for more than one child with disability. Interviewed caregivers mostly belonged to poor, large size families and are mostly unemployed. The study points out that the overall caregivers' wellbeing score was 58%, 20% less than the wellbeing of the general population of the Gaza Strip. Similarly, the overall caregivers' Parental Stress was reported at 55.2% with parental distress domain eliciting the lowest scores (52.4%).*

Although there are many difficulties facing caregivers of children with disabilities, the financial burden was the mostly prominent one that caregivers were challenged within securing medical services (83%), education (41.8%) and recreational activities (38.4%). Transportation and adaptation of public places were also major challenges that keep caregivers and their children home-bound.

Support provided to families is mostly provided through charity lenses, mainly from social assistant programs that are not adequately disability sensitive. Caregivers received little education and counseling on how to deal with their children. Most of the support provided to children with disability was provided by close family members (above 70%), while other people in the community like taxi drivers, salesmen at shops, people at religious or recreational places were showing less support. Sadly, only nearly half of caregivers felt that doctors, nurses and other health providers are supportive. However, even those who are theoretically supportive within and outside the family are not providing actual help and as the circle widens support decreases.

Regarding forgone opportunities, 75.25% had difficulties in securing recreational activities and leisure time and also forgone opportunities for socialization, attending social events and mixing with other people challenges as well as employment. With regard to the time use among caregivers, it was found that caregiving took a lot of time leaving much less time for rest, sleep and leisure activities, as the meantime for these combined was 3.7 hours daily and this affected their level of stress and wellbeing score ($r = 0.324, 0.260$, p-value $=0.001$).The previous results were similar to qualitative results.

Moreover, inferential statistics showed that having an older child, living in a poor, extended and large size family and having more than one child with disability are being associated with lower wellbeing scores and a higher level of stress with statistically significant differences in comparison with counterparts. Strangely, the type of disability and gender of the child with disability did not show differences in the level of wellbeing.,

Conclusion *Caregivers with children with disabilities need to be targeted and supported through psychosocial programs, providing counseling and information, respite care and also financially supported. There is a need to positively change services providers and the community members attitudes about disability and also modifying the package of services to be more disability sensitive services.*

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List of Abbreviations

ADL	Activities of Daily Living
ASD	Autism Spectrum Disorder
CBR	Community-Based Rehabilitation
CP	Cerebral Palsy
CWDs	Children with Disabilities
DC	Difficult Child
FGDs	Focused Group Discussions
GS	Gaza Strip
HH	Household
ID	Intellectual Disability
IDI	In-depth individual interviews
KII	Key Informant Interviews
LS	Life Satisfaction
MOE	Ministry of Education
MOH	Ministry of Health
MOSD	Ministry of Social Development
NGOs	Nongovernmental Organizations
OECD	The Organisation for Economic Co-operation and Development
PA	Palestinian Authority
PCBS	Palestinian Central Bureau of Statistics
P-CDI	Parent-Child dysfunctional interaction
PD	Parental Distress
PIMD	Profound Intellectual and Multiple disabilities
PNCTP	Palestinian National Cash Transfer Program
PSI	Parental Stress Index
PWD	People with Disability
QoL	Quality of Life
UN	United Nations
UNICEF	UN Children's Emergency Fund
UNRWA	United Nations Relief and Works Agency for Palestine Refugees in the Near East
WHO	World Health Organization

Chapter One

Introduction

1.1 Background

Being a parent of a child makes caregiving a natural role, this role takes a different significance when child experiences disability where life extremely changes, as parents specially the mother face a challenging caregiving responsibility. Having a Child with Disability (CWD) has an important effect on parents in all different domains of their life, as caregivers offer a unique form of giving. CWDs are part of their caregiver's life and their disability has its consequences on the Quality of Life (QoL) which can be considered as a concept that identifies what is important, necessary and satisfying in human existence (Schippers 2010). Furthermore, there is great attention globally about exploring the QoL of people specially when related to one of the marginalized groups like CWDs. In addition, there are several factors that affect the QoL of the caregivers for example; their feelings about their performance as a caregiver, possible physical health problem due to lifting, quitting their jobs and social activities (Sulch & Kalra, 2003). Significantly, research has shown that levels of parenting stress might be increased among those having CWDs compared to families having children without disability (Dardas & Ahmad, 2014). Also, parents of CWDs may react negatively with changes in their social life and may experience considerable stress as well as feelings of depression, anger, shock, denial, self-blame guilt, and confusion (S'lungile, Ntinda & Hlanze, 2015). Therefore, the sequence and time needed for adjustment are different for every parent (S'lungile, Ntinda & Hlanze, 2015).

Clearly, children disability is a worldwide interest, according to the World Disability Report (2011), the global burden of disease estimates the number of children aged 0–14 years experiencing "moderate or severe disability" at 93 million (5.1%), with 13 million (0.7%) children experiencing severe difficulties. Moreover, a review of the literature in low- and middle-income countries reports child disability prevalence from 0.4% to 12.7% (WHO, 2011).

Eventually, all caring parents' ultimate goal is to give their child the best for QoL maximizing their potential and to do so the caregiver QoL is a crucial area to focus on to ensure a better understanding of the needs of caregivers and consequently better wellbeing. Because disability puts increasing social and economic demands on all countries, decision-

makers and governments need to develop policy-driven initiatives based on a clear understanding of the importance of personal, social and cultural factors that contribute to QoL among caregivers. This research provides information that could contribute towards developing such supportive policies to caregivers of CWDs.

1.2 Research problem

The prevalence of disability in Gaza is 6.8% (PCBS, 2018) which is higher than the internationally reported 5% (WHO, 2011), with a proportion of families with more than one person with disabilities reaching 31.7% in the Gaza Strip (GS) (Jones et al., 2016).

In Palestine, the prevalence of disability has been adequately studied, already we know its prevalence. Also, the wellbeing of people with disabilities (PWD), traumatized or people under specific conditions were studied in GS. Still, little is known about the wellbeing status of caregivers of CWD and the suffering that they face. We know the less about the burden of caregiving among caregivers of CWDs, so it's worth studying. This study fills important gaps in information about the challenges facing caregivers of CWDs. The study answers unanswered key questions about what are the key challenges facing caregivers of CWDs, their QoL, stress level they experience, and their forgone opportunities due to caregiving responsibilities.

1.3 Justification

The importance of the study is evident theoretically in helping to develop a deeper and more comprehensive understanding of the disability burden on caregivers. It highlights the extent to which there is support to CWDs, and their caregivers and the needed support to overcome the social, psychological and economic challenges associated with disability as faced by caregivers in Gaza. The researcher's work in the field of physiotherapy and teaching is also an opportunity to support caregivers of CWDs. So, the skills and accumulated knowledge created by this research will be reflected on her experiences while serving caregivers of CWDs or during teaching. Moreover, this is the first study of its kind in Gaza, according to the researcher's knowledge, which deals with this issue, which will contribute to creating community and institutional awareness of this issue.

The study will also contribute to enriching the Arab library in the field of disability. Moreover, this study will encourage researchers in different disciplines to further research in the fields and implications of disability on family life. This accumulation of knowledge

will contribute to the desensitization process to support caregivers and helping them cope with their challenges.

Additionally, this study may contribute to motivating relevant institutions to develop programs and plans to provide support to caregivers of CWDs. Furthermore, it helps legislators to enact new legislation or activate the existing legislation to fulfill the rights of CWDs and their families to help them adapt and ensure their families a decent life in terms of increasing the quality of the services provided to them and improving them.

1.4 Aim of the study

The aim of this study is to assess the QoL of CWDs in order to provide recommendations that ultimately contribute to improving the wellbeing and parental stress (PSI) for caregivers of CWDs and thus improving their physical and psychological wellbeing.

1.5 Study objectives

1. To explore the wellbeing and PSI among caregivers of CWDs.
2. To assess the available support services for the caregivers of CWDs.
3. To ascertain the challenges facing the caregivers of CWDs.
4. To examine variations in the wellbeing and PSI among caregivers of CWDs in reference to characteristics and disability-related variables.
5. To develop recommendations to improve the QoL of caregivers and CWDs.

1.6 Research questions

1. What is the wellbeing status of the surveyed caregivers?
2. What is the burden of caregiving on the wellbeing and PSI among caregivers?
3. How wellbeing and PSI status differs in reference to demographic and socioeconomic status such as age, gender, family size, family type?
4. Which characteristics in relation to the disability of child that affect wellbeing and PSI of the caregiver? how wellbeing and PSI differ in reference to disability-related variables such as type of disability, degree of dependence, need for special care or services?
5. What are challenges caregivers of CWDs face such as the forgone opportunities for education and work that are lost from the caregiver?
6. How social capita of caregiver is affected by the caregiving process?

7. To what extent does social stigma influence the wellbeing of the caregiver?
8. What are the barriers faced by the caregiver to live a quality life?
9. What are the possible interventions that can be significant to improve the QoL of the caregiver and his /her CWD?

1.7 Context of the study

1.7.1 Gaza demographic characteristics

The GS is one of the most densely populated in the world with a population of 1,899,291 with an area of 365 km and a density of 5,203 per km2 (PCBS, 2018). The GS is divided into five governorates: North Gaza, Gaza City, Mid Zone, Khan Younis, and Rafah. The average household (HH) family size is 5.6 (PCBS, 2018). According to the PCBS, the majority of the GS population is refugees (67%). A large proportion of the population is youngsters (0-17 years of age) which is 48.0% as shown by the Preliminary Results of the Population, Housing and Establishments Census (2018). The high number of children 48% according to the PCBS (PCBS, 2018) will increase stress on the health system and will increase the demand for targeting vulnerable groups such as CWDs.

1.7.2 Political context

The GS has experienced many wars and long occupation, in the last 10 years Gaza faced 3 wars in 5 years (2008, 2012, 2014) and nowadays it is facing a very difficult living situation starting from blockade to internal division. This situation resulted in many injuries and congenital problems due to circumstances experienced during wars; for example, in the war of 2008/2009, and 2014 Israel used Phosphorus bombs in Gaza which has serious damaging long-standing effects on people and environment. Furthermore, the newest injuries that are continuously increasing till this moment due to the confrontations and the action called "The March of Return" which resulted in till now 32,529 injuries with more than 20% under the age of 18 according to the Ministry of Health reports (MOH) (2019). Consequently, the number of PWDs including children was rapidly rising as a result of the excessive Israeli occupation of the use of force in all its forms against the Palestinian people.

1.7.3 Socioeconomic context

The economic status in Gaza is difficult where poverty affecting 38.8% of the total population (Courbage, Abu-Hamad & Zagha, 2016). Of the population of Gaza 48.2% of youth are unemployed (PCBS, 2018). For years, there are mobility restrictions imposed on

GS and almost all movements controlled by the Israelis, which makes a few people and a limited number of goods are allowed to cross in and out. The main sources of livelihood in the GS are employment in the services sector which lately was affected by decreasing salaries of the employees. The proportion of Palestinians in Gaza who had a monthly income below the national poverty line is 76.1 % (Courbage, Abu-Hamad & Zagha, 2016).
All these conditions of poverty significantly increase someone's chances of being disabled by malnutrition, disease or injury (Nielsen, 2012). Many Gazans are food insecure, due primarily to a lack of economic means, rather than a shortage of food. More than half of the people in Gaza are either food insecure (44%) or vulnerable to food insecurity (16%) (United Nation-UN, 2012). Another aspect related to the economic status is social protection, the Palestinian Authority (PA) manages social protection program through the Ministry of Social Development (MOSD), some social protection support through the Palestinian National Cash Transfer Program (PNCTP) and health insurance for those with disabilities. Most of the other needed services are supposed to be delivered at the intermediary and local levels, though not all are delivered as they should. Crucially, because of both the ongoing conflict with Israel and the intra- Palestinian divisions, services in Gaza often fall short of the mark (Jones et al., 2016). All the previous socioeconomic environment surrounds the caregivers and applies a burden on the caregivers QoL and increases stress levels.

1.7.4 Cultural context

The Palestinian culture encourages fertility and having many children out of religious and social beliefs, this provides a type of social security and protection for the family and the tribe against others (Courbage, Abu-Hamad & Zagha, 2016). Marriage in Palestine is at the same time precocious (unusually early) – which therefore leads to a high fertility rate while the total fertility rate in Gaza is 4.06 per 1000 (Courbage, Abu-Hamad & Zagha, 2016). Early marriage is still found notably in the Palestinian society with more than 50% of females aged more than 15 are married. 36% of married women have been married before the age of 18 years and 5% married before the age of 15 years (PCBS, 2013). This has its consequences on economic and health status of the whole family which may contribute to the existence of a disability.
Adding to the problem of being early married on the mother who is very young another burden of a CWD. In addition to consanguineous marriages which according to (PCBS, 2013) data showed that 30.2% of marriages forever married women (15-29) years were

married off first consanguinity linkage to their husbands which may contribute to increasing the risks on health and increasing the risk of disability. Being married this way may put additional responsibilities in front of the family on the mother or the caregiver which has its stressful effect.

Furthermore, Palestinian CWDs typically face a particularly dire situation, given the levels of cultural stigma directed at disability and the protracted conflict that surrounds them, which has devastated infrastructure, fractured the economy and overwhelmed service providers (Jones et al., 2016). The stigma is faced predominately by the caregiver and may cause negative consequences. While caring for CWDs was a burden born disproportionately by mothers, Palestinian culture does not encourage the day-to-day involvement of fathers. Moreover, gender-based violence is common, with both in-laws and husbands emotionally, verbally and physically abusing mothers, and in some cases, mothers of CWDs are forced to accommodate co-wives as husbands seek to produce healthy children (Jones et al., 2016).

1.7.5 Health system

Health and rehabilitation services for CWDs, like the health services provided to the broader population, are provided by different stakeholders in Gaza. MOH is responsible for providing general health services to non-refugees, while the UN Relief and Works Agency for Palestine Refugees in the Near East (UNRWA) provides equivalent services to Palestinian refugees. Furthermore, while MOH provides health care services in hospitals located in central cities, large numbers of private hospitals and Nongovernmental Organizations (NGOs), such as the Palestinian Red Crescent, provide specialized medical care alongside government hospitals (Jones et al., 2016). Specialized rehabilitation services are provided mainly by national NGOs that are highly qualified and equipped with superior quality medical and rehabilitation facilities. Their services are covered either privately by patients or through referral by MOH or UNRWA (Jones et al., 2016).

The key services for CWDs provided at the national level are health and education, with some social protection support through the PNCTP and health insurance for those with disabilities. Most of the other needed services are supposed to be delivered at the intermediary and local levels, though not all are delivered as they should (Jones et al., 2016).

1.7.6 Current status of disability

The prevalence of disability in Palestine based on the "narrow" definition of disability (a lot of difficulties or cannot at all) and a prevalence of 6.9% using the 'wide' definition (also including some difficulty) (PCBS, 2012). As known Gaza had gone through wars which were devastating and left thousands of people dead and injured and many homes were destroyed adding to the blockade since 2007. Many wounded suffered from permanent disability, according to hospital reports until today the March of return is still ongoing raising the number of injured people who may be added to PWD. According to data from PCBS (2018), the prevalence of difficulties among persons increased during the last 10 years, where it was 4.7% in Palestine in 2007 (3.7% in GS) then increased to 5.8% (6.8% in GS) in 2017. As for Gaza, the highest prevalence was reported in Gaza governorate, with 2.5%, followed by North Gaza, Rafah and Deir Al Balah governorates, with 2.4% each (PCBS, 2012). Eight types of CWDs are in Palestine, in adults, mobility-related impairments are the most common type of disability, making up nearly half of all disability cases in both Gaza and the West Bank. Learning disabilities are the second most common type (PCBS, 2012). Regrading CWDs, the most prevalent type is communication or speech disability at 24.4% of all cases, followed by mobility-related disabilities at 19.3% (Jones et al., 2016). Among adults, illness is the most common cause of disabilities (37.4%), then aging (13.5%) or congenital conditions (9.6%) (PCBS, 2012). While in children, congenital causes are the most frequent (29.6%), followed by the result of illness (24%), birth-injury related (15%) or hereditary (12.2%) (Jones et al., 2016).

Activities of daily living (ADL) are of importance that constitutes a challenge where 34.2% PWDs ADL (Jones et al., 2016), moreover 37.4% of PWDs face difficulties in bathing and washing. Also, 29% face difficult in dressing by themselves and using the toilet (25.9%) indicating that females face more difficulties than males in performing ADL. Furthermore, CWDs face more difficulties than older ones, and children with multiple disabilities and with mobility-related disability face more difficulties than other types (Jones et al., 2016).

As for adapting the environment, Palestinian environments were rarely adapted to meet the needs of CWDs, schools, health clinics, transportation even homes are mostly not adapted (Jones et al., 2016). 24.6% of PWDs need ramps at home, 33.7% toilet adaptation and other needed adaptations like kitchen and need for an elevator in their homes (Jones et al., 2016).

Another important limitation in adaptation or even access is transportation, where more than 70% could not use public transportation adding to mobility-related disabilities who 34.7% of them need adaptations to transportation in order to reach work, similar to visually related disabilities and even mental related disabilities (Jones et al., 2016). Specific services such as medical and rehabilitation services were underutilization where only 7.7% of PWDs received those services (Jones et al., 2016). Education is also a field that has unsatisfying outcomes for PWDs where 31.5% of them had never attended education not to mention who stopped their schooling (22%) (Jones et al., 2016).

It is vital to have a clear view of the legal aspects that are presently in place where a legal framework Law No.4 (1999) is present citing the rights of the PWDs based on equity principles, it provides for the right of PWDs to equality before the law and to non-discrimination, as well as to housing, health care, and rehabilitation, travel and work and participation in cultural life. The law identifies MOSD as the government agency responsible for fulfilling these commitments and requires that the ministry coordinate with all relevant and competent bodies to secure the welfare and rehabilitation of PWDs (Palestinian Liberation Organization/ Palestinian Authority,1999). MOSD adopted the executive by-laws for the law's enforcement in 2004. According to the Palestinian National plan for 2014-2016, the enforcement mechanisms and tools are lacking, and resources within the national budget to meet the needs of the PWD are limited also, little accomplishments have been made so far in the implementation of the law, especially with the lack of financial resources as the main restrictive factor. Also, the National plan described the Policies relate to disability that they are deficient in most of the sectors, with the exception of the education sector, where the Ministry of Education (MOE) is adopting an inclusive education approach, coupled with support to special needs education schools. Most of the medical and rehabilitation services are offered mainly by the NGO sector. Vocational and livelihood services are largely deficient with few exceptions of vocational centers run by the private and government sectors. The provisions of the disability law requiring the allocation of 5% of jobs in large institutions to PWDs are not enforced even by governmental organizations.

Services provided for PWDs are by three main categories of actors; public authorities, service providers and international agencies (Jones et al., 2016). The main services for CWDs provided at the national level are health and education, with some social protection support through the PNCTP and health insurance for those with disabilities. The intermediary and local levels are supposed to deliver the other needed services, though not

all are delivered as they should (Jones et al., 2016). MOH provides general health services to non-refugees with covered health insurance, while the UNRWA provides alike services to Palestinian refugees in Gaza. Furthermore, large numbers of private hospitals and NGOs, such as the Palestinian Red Crescent, provide specialized medical care together with government hospitals (Jones et al., 2016). National NGOs provide the specialized rehabilitation services that are highly qualified and equipped which are covered either privately by patients or through referral by MOH or UNRWA (Jones et al., 2016). Rehabilitation services (e.g. assistive devices, speech and occupational therapy, physiotherapy, home modifications, community- and home-based care) are also provided by UNRWA to refugees with disabilities, applied primarily through NGO-run community-based rehabilitation (CBR) centers and outreach activities (Jones et al., 2016).

As for education, CWDs opportunities vary depending on the type of disability, the economic status of the family and the residence. MOE aims to provide equal opportunities to all school-age CWDs that it adopts inclusive education. However, the majority of CWDs who have access to formal education is with mild to moderate physical disabilities rather than cognitive disabilities (Jones et al., 2016).

Finally, the gap analysis that have been done by UNICEF (United Nations Children's Emergency Fund) about CWDs situation in Palestine found that the Palestinian CWDs are highly vulnerable, and extremely poor, under-supported to realize their rights to an appropriately tailored education and health care, have very few opportunities to participate in the social activities required for healthy development and poorly protected from abuse and exploitation.

1.8 Operational definitions

- **Quality of life**: The individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals. This includes the QoL as general self perceiving wellbeing using WHO wellbeing scale 26 and parental stress specific for the situation of disability existence.
- **Wellbeing:** A positive outcome that is meaningful for people, because it tells us that people perceive that their lives are going well (CDC, 2018) measured by WHO wellbeing scale 26.
    - High level wellbeing: The status in which a person describes his/her life to be matching his/her own standards. i/e: the good life is the one close to the person‟s

ideal preferences. When operationalized, it reflects responses with points 4 and 5 in the used Likert scale from 1 to 5 (75-100%) as concluded from WHO (1995) manual.

- Moderate level wellbeing: The status of at which, a person‟s life reality is around half the way into how his/her ideal preferences. The assumption is that the moderate QOL level is expected from the responses lie around the mid of the used Likert scale when operationalized (50-74%) as concluded from WHO (1995) manual.
- Low level wellbeing: The status at which a person describes his/her life to be far away from his/her ideal preferences; the responses reported will be closer to the minimum anchor of the evaluation scale when operationalized (below 49%) as concluded from WHO (1995) manual.

- **Parental stress index:** A distinct type of stress that arises when a parent's perception of the demands of parenting outstrips his or her resources in relation to his/ her to all relevant in order to be sensitive to CWDs (Coulacoglou & Saklofske, 2017). According to the used coding approach, higher scores mean positive interaction and less scores and low scores mean higher level of stress**.**
- **Caregiver**: The mother, father, siblings who provide practical, day-to-day unpaid support for a person unable to complete all of the tasks of daily living (Savage and Bailey 2004).
- **Child**: A human being below the age of 18 years unless, under the law applicable to the child, the majority is attained earlier.
- **Child with disability**: a child from 0-18 years old having disability and registered as a person with disability at a disability related organization .

Chapter Two

Conceptual framework and Literature review

2.1 Conceptual framework

2.1.1 Quality of life

QoL is the sum of a range of objectively measurable life conditions experienced by an individual which include physical health, personal circumstances, social relationships, functional activities and pursuits, and wider societies and economic influences. Subjective response to such conditions is the domain of personal satisfaction with life (Hsiao& Nixon, 2008). This will include the wellbeing domain and parental stress domain.

According to the literature, components of the WHO wellbeing scale 26 (WHO, 2004) are four domains:

2.1.1.1 Physical health

The lifestyle behavior choices you make to ensure health, avoid preventable diseases and conditions and live in a balanced state of body, mind and spirit (American Association of Nurse Anesthetists, 2019). They include the level of pain, energy, and sleeping. This domain explores the extent to which different sensations interfere with life and how they affect wellbeing.

2.1.1.2 Psychological health

This means the individuals' perceptions of their cognitive and affective state; it hypothetically reflects the affective part and mental composition of QoL evaluation. They include positive feelings, thinking, learning, self-esteem, body image and negative feelings which possibly affect wellbeing status.

2.1.1.3 Social relationships

Involves dynamics of social interactions, bounded and regulated by social and cultural norms, between two or more people, with each having a social position and performing a social role (Yusof 2009). This includes personal relations, social support, and sexual activities. These aspects are thought to be interlinked with the QoL.

2.1.1.4 Environment

The environment represents part of the cognitive and normative QoL evaluation and reflects their thoughts about the objective material context at which people live. It includes the physical environment and feeling safe, finically secured, access to health care and its quality and access to skills and information. These aspects are thought to be regarded in the persons' QoL and it could either improve or adversely affect it.

2.1.2 Parental stress index

PSI is a screening and triage measure for evaluating the parenting system and identifying issues that may lead to problems in the child's or parent's behavior (Abidin, 2012). It concentrates on three major domains of stress: child characteristics, parent characteristics and situational/demographic life stress (Abidin, 2012).

2.1.2.1 Parental distress

The extent to which parents feel competent, restricted, conflicted, supported, and/or depressed in their role as a parent.

2.1.2.2 Parent-Child dysfunctional interaction

The extent to which parents feel satisfied with their child and their interactions with them.

2.1.2.3 Difficult child

How a parent perceives their child to be, whether the child is easy or difficult to take care of.

2.1.3 Caregiver's demographic characteristics

QoL of the caregiver may be varied according to individual characteristics which are in this study: Demographics such as age, gender, relationship with CWD, Education. In addition to employment, economic status including monthly income, source of income, assistance both cash and in-kind and HH characteristics. These aspects may contribute to QoL either positively or negatively.

2.1.4 Child individual characteristics

Characteristics assigned to age, sex, education. Some studies indicated that variations among child characteristics might be a factor contributing to the burden on the caregiver.

2.1.5 Service provision

These are factors related to the availability and utilization of available health services by the mother (caregiver and her CWD). This includes awareness, information, health services, education, residential care, and environment. These factors may have an effect on the QoL of caregiver.

2.1.6 Difficulties faced by caregiver related to child disability

These are factors related to disability which have distinctive features that may influence the caregiver experience which are: nature of the disability, reason of disability, needed care, daily activities. A number of studies have investigated whether disability type has an impact on caregivers QoL (Browne 2010). As evident from research, there is a close relationship between the duration and severity of disease with that of QoL of informal caregivers (Ferrara et al., 2008). In addition to the difficulties faced by caregiver due to disability-related to education, ADL.

2.1.7 Cultural norms

These factors hypothesize the context effects of norms, tradition, dominant patterns of behaviors. They include: dominant cultural norms, people's support and perceptions about disability also discrimination faced while taking services.

2.1.8 Financial burden

This represents financial status and includes income and wealth, affordability of basic services , dependency on external aid, sources of aid, major difficulties to secure assistive devices and needs, these factors could potentially influence the QoL.

2.1.9 Forgone opportunities

These are consequences that are related to the opportunities that are lost as a result of caring of CWD such as education, work, and social capita. Such consequences deserve to be studied as a sequence of the caring process that may have an effect on the QoL of the caregiver.

2.1.10 Psychosocial burden

These are consequences of social and cultural behaviors that may be produced by the existence of CWD like stigma, and social isolation burden, feeling ashamed and other psychological consequences.

2.1.11 Time use

A time-use survey is a statistical survey which aims to report data on how, on average, people spend their time.

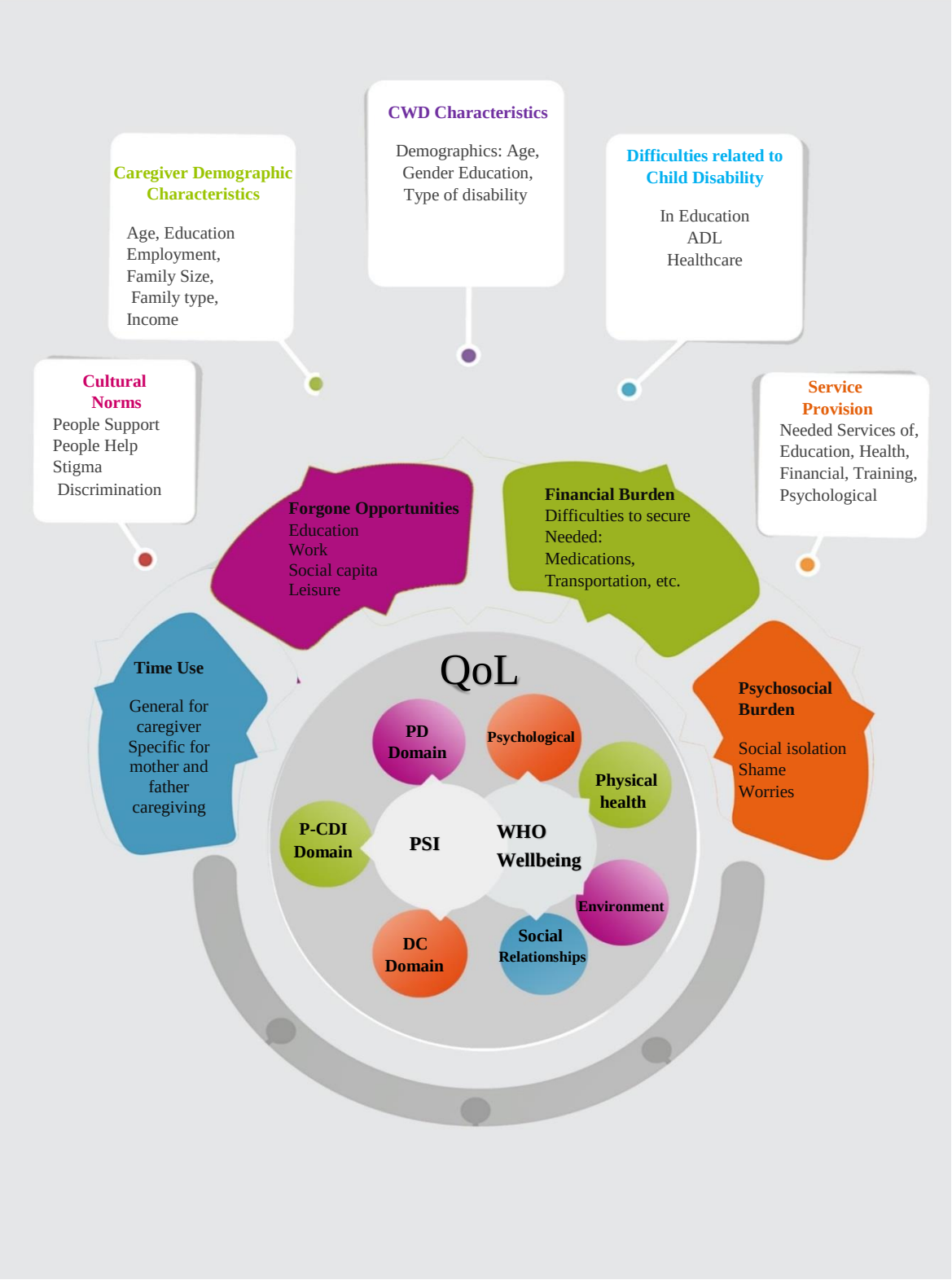

Figure (2.1): Conceptual framework of the study

2.2 Literature review

2.2.1 Definition of disability

There are many definitions for disability, according to Tanaka & Seals (2003) disability is an impairment that may be cognitive, developmental, intellectual, mental, physical, sensory or some combination of these. It substantially affects a person's life activities and may be present from birth or occur during a person's lifetime. Disability is an umbrella term, covering impairments, activity limitations, and participation restrictions. So, an impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Disability is thus not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives (WHO, 2011).

2.2.2 Epidemiology of disability

In 2012, the WHO estimated a world population of 6.5 billion people. Of those, nearly 650 million people, or 10%, were estimated to be moderately or severely disabled (WHO, 2011). By one widely used estimate, some 93 million children – or 1 in 20 of those aged 14 or younger – live with a moderate or severe disability of some kind (Jones et al., 2016). In Palestine, 5.8% of the population is with a disability and in Gaza 6.8% (PCBS, 2018). In a different report and different definition of disability CWDs in Gaza were 12,127 with 1.6% prevalence, with highest in the North Gaza 26.3% and the least in Rafah with 13.1% (PCBS, 2012). Children with one type of disability were 52% and the rest were with more than one disability (PCBS, 2012). As for types of disability there are eight types of disability in children which are: visual, hearing, mobility, communication, remembering and concentrating, intellectual and learning, psychological and mental and multi-disabilities (Jones et al., 2016). The highest disability is communication disability with 24.4% and the least is Hearing with 14.5%. Furthermore, the highest cause of disability is congenital causes with 42% then delivery-related causes with 16.2% then diseases with 16% (Jones et al., 2016).

2.2.3 Quality of life

QoL describes an individual's perception of his or her position in a context in relation to concerns and goals, it is a complex, multifaceted construct that requires multiple approaches from different angles. QoL was measured as a multi-dimensions issue: physical, psychosocial, social, environmental (Aziz, Hutchinson & Maltby, 2014).

2.2.3.1 WHO wellbeing

In the literature, the term 'quality of life' is also often referred to as 'well-being. wellbeing is a multi-dimensional complex concept. Similar to the complexity of defining health, understanding wellbeing is even more challenging (Chandra & Ranaweera, 2009). Thus far, there is no single definition of wellbeing, but there is agreement that wellbeing depends on people's evaluation of their lives in both thoughts and feelings. It includes the presence of positive emotions and moods (e.g., contentment, happiness), the absence of negative emotions (e.g., depression, anxiety), and satisfaction with life, fulfillment and positive functioning (Diener, 2009; CDC, 2009). A thorough understanding of subjective well-being requires knowledge of how objective conditions influence people's evaluations of their lives. Similarly, a complete understanding of objective indicators and how to select them requires that we understand people's values and have knowledge about how objective indicators influence people's experience of well-being (Theofilou 2013). In essence, life satisfaction (LS) is a subjective assessment of the quality of one's life (Theofilou 2013). Judgments of LS have a large cognitive component, it is essential to mention that subjective well-being has both an affective (i.e., emotional) and a cognitive (i.e., judgmental) component. The affective component consists of how frequently an individual report experiencing positive and negative affect (Theofilou 2013).

In a study, Malhotra, Khan & Bhatia (2012) examined QoL of parents of children with mental retardation and autism and found that all the four domains of QoL were lower (i.e., physical health, psychological well-being, social relationships, and environment) compared with parents of healthy children. Another study, Noor (2003) has noted that parents of children with Intellectual Disabilities (ID) face problems like absenteeism in the workplace, inattentiveness in job activity, disturbances in mental and physical health, marital dissatisfaction, and poor overall well-being. Lower QoL scores of primary caregivers of brain tumor children were found in a study compared to normal scores of healthy adults (Chien et al., 2003). Zuurmond et al. (2015) found that QoL scores were

significantly poorer ($p<0.001$) for caregivers of a child with cerebral palsy (CP) compared to scores from families that did not have a CWD. Caregivers reported high levels of stress, anxiety, isolation, stigma, physical tiredness, and lack of time to complete everyday tasks. From Jordan which is one of the nearest countries to Palestine, a study of QoL among Jordanian families that have CWDs, QoL scores turned to be at a moderate level (Awamleh, 2015). Generally, the QoL in Palestine, particularly in the GS is very poor, people in Gaza still worse than they were in the 1990s (UNSCO, 2012). A study was made in Gaza on patients with cancer the global QoL was less than half of the full score (Shamallakh & Imam, 2017). Similarly, Khleif & Imam (2013) conducted a triangulated study in the West Bank on the cancer patients where the qualitative results revealed that there were several unmet needs such as financial aid, pain management, properly equipped health-care facilities in their vicinity, availability of medication, eradication of stigma, improved communication by the health-care team with the patient and psychosocial support, home nursing care, and palliative care.

2.2.3.1.1 Physical health domain

This domain reflects ADL, dependence on medicinal substances, energy and fatigue, mobility, sleep and rest and work capacity. Most of the studies conducted on the people who suffer from physical health illustrated that their QoL very low and especially in the physical domain, which had an effect on the other domains, particularly on the psychological domain. On average, around 70% of the OECD population report good or very good health, although there is a large variation across countries. Respondents from the United States, New Zealand, Canada, and Australia report good or very good health most often, compared with lower levels in the Slovak Republic, Japan, and Portugal (Durand, 2015). Olsson, Larsman & Hwang (2008) examined the well-being of the caregivers; particularly how satisfied the caregivers of children with ID are with their life and how healthy they are and found that the parents of children with ID exhibited a lower level of well-being compared to the parents of children without disabilities.

In a focused look at caregiver's study in the United States of America (USA) that made by the National Alliance of caregiving (2009), caregivers of CWDs are twice as likely as the general adult population to say they are in fair/poor health (National Alliance of caregiving, 2009). Physical tiredness of the caregiver, combined with a lack of time to conduct everyday HH chores, were key themes identified by the caregivers in the in-depth interviews in the study conducted on Bangladesh caregivers of CP children, the mother

was most often the sole caregiver, and also frequently combined this with livelihood activities (Zuurmond et al., 2015). In some cases, the child needed to be carried or supported by the caregiver throughout the day, which made it difficult to undertake even basic HH activities (Zuurmond et al., 2015). Seventy percent of mothers of children with physical disabilities have low back pain. There is a higher incidence of migraine headaches, gastrointestinal ulcers, and greater overall distress (Chambers & Chambers, 2015). In Jordan, Awamleh (2015) pointed out that the worst score of all domains of QoL among families of CWDs was the physical health domain where it scored 56.3%.

Israeli attack in 2008, pointed that the mean Health-Related QoL score (range 0–100) for the physical domain was 69.7% which was one of the results in a study aimed to document the (HRQoL) of people living in the GS 6 months after 27 December 2008 to 18 January 2009 (Abu- Rmeileh et al., 2011).

2.2.3.1.2 Psychological domain

The psychological domain reflects the subjective perception of individuals about different aspects like bodily image and appearance, negative feelings, positive feelings, memory, and concentration. Psychological stress had a significant impact on the global domain of QoL. Most of the local and international studies pointed out that the emotional function was more closely associated with overall satisfaction (Al Himdiat & Qammar, 2018). Chambers & Chambers (2015) stated in their research that there is an impact of caring for the child in terms of emotional functioning and worry and they were two of the lowest QoL scores for families. Correspondingly, high levels of worry and anxiety felt by the caregiver were two of the most common problems. These feelings were commonly explained by the lack of support in caring for the child, physical exhaustion, very low levels of knowledge about disability, and high levels of stigma related to having a disability (Chambers & Chambers, 2015).

In a recent study about caregivers for autism spectrum disorder children (ASD), mothers of a child with ASD are highly burdened and more likely to report poor or fair mental health than mothers in the general populations (Al-Dujaili & Al-Mossawy, 2017). A case-control study in Ahvaz, Iran revealed that mothers of children with CP suffer more stress than mothers of healthy children. In addition to psychological pressure, stress, and depression, low QoL (54.1%) for mothers of children with CP is related to concerns about their child's future. On the other hand, mothers of healthy children have more time to spend and can participate more fully in social activities, entertainment, and business (Borzoo, Nickbakht

& Jalalian, 2014).In Arab countries like Algeria, a study was conducted to indicate the QoL among mothers of children with mental disabilities where it revealed a low score of the psychological domain (31.61%) (Maghnia, 2018). In contrast to Awamleh's study (2015), the psychological domain for mothers of CWDs was 61.3%. Variation is wide which may be attributed to the context, individual differences, and other disability-related factors.

In GS, available data from the reviewed studies were not specifically for caregivers but some of them concentrated on psychological wellbeing. In a 2004 study, Palestinian adolescents recorded the lowest QoL scores out of 35 participating countries (Giacaman et al., 2004). Using the Palestinian QoL in 2005 was found to be 'very poor'. Palestinian scores were significantly lower in all four domains (physical, psychological, social and environmental) than most of the 23 countries participating in WHO's International Field Trials. In addition, the study participants reported high levels of fears, threats to personal and family safety, and fears about their future and the future of their families (Giacaman et al., 2004). Moreover, the study revealed that one in two Palestinians fear for themselves in their daily life, also almost all Palestinians fear for their family's safety in their daily life. As for worrying, almost all Palestinians worry over their future and the future of their families and almost one in two Palestinians live with distress, anxiety, worry, and grief. In addition, more than one in three Palestinians feel deprived and more than one in three Palestinians feel that suffering is part of their life while more than one in three Palestinians are fed up with life (Giacaman et al., 2004).

2.2.3.1.3 Social relations domain

This domain investigates Personal relationships, Social support, Sexual activity. According to WHO (1995), social relationships intend to reflect on individuals' perceptions of interpersonal relationships and social roles in their life (WHO, 1995). Beyond the intrinsic pleasure that people derive from spending time with others, social connections have positive spill-over effects for individual and societal well-being (Durand, 2015).

In a study was examining the gains and losses of caregiving, the respondents reported experiencing: no social life and no opportunity to start a relationship, no opportunity to have an intimate relationship with spouse, loss of personal sense of self, loss of free time/freedom, having to wait to have more children, loss of ability to sustain normalcy in public, understanding that child will be different from other children, loss of the original

dreams for family member to be independent, siblings have to sacrifice and have a different childhood, with increased responsibilities, difficult for grandparents and other family members (Raver & Michalek, 2011).

In some studies focusing on the QoL of caregivers of children with a chronic condition, the social domain was the most significant indicator of poor QoL, caregivers often have significantly poorer social relationships compared with parents of healthy children (Karande & Kulkarni, 2009). Social support can be provided both informally, by family, friends, neighbors, social groups and so on, and formally, by professionals and agencies. There is some evidence in the literature that the amount and quality of social support available to caregivers is an important factor in moderating the impact of caregiving (Savage & Bailey, 2004). Kerenhappachu & Sridevi (2014) stated in a study on caregiver's burden and perceived social support in mothers of children with mental retardation where mothers of showed significant difference on caregivers burden than the mothers of normal children in the areas of general strain, disappointment, and emotional involvement, there is also a significant difference in social support for mothers of children with mental retardation and mothers of normal children in the areas of support seeking and actually received support, they were experiencing more caregiver's burden and seeking more social support than the mothers of normal children (Kerenhappachu & Sridevi, 2014).

An interesting survey applied in the OECD countries revealed that on average, more than 90% of people declared that they had someone to count on in times of need. According to this measure, among OECD countries support networks appeared to be weakest in Turkey, Korea, Portugal and Estonia, and strongest in Iceland, Ireland, New Zealand, and Denmark. When excluding OECD countries at both ends of the distribution, however, levels of social support are very similar across countries, ranging between 85 and 95% (Durand, 2015). Kareem & Ali (2014) had studied QoL for Parents with Children who have Autism in Erbil Iraq and revealed in his study that social relationship domain mean score for mothers (53.62%) was lower than fathers (58.62%) and that the QoL is adversely impacted for parents of children with autism. In Gaza, the social relationships domain was investigated for adults generally by Al-Bayoumi (2014) where the overall score was 75.9% which is considered relatively good (Al-Bayoumi, 2014).

2.2.3.1.4 Environmental domain

Regarding the environmental domain, it has subdomains based on the WHO definition which include (financial resources, freedom, physical safety and security, health and social care: accessibility and quality, home environment, opportunities for acquiring new information and skills, participation in and opportunities for recreation/leisure activities, physical environment; pollution/noise/traffic/climate, and transport). Environmental quality is a key dimension of people's well-being, as QoL is strongly affected by a healthy physical environment (Durand, 2015).

In fact, people's lives are strongly affected by the healthiness of their physical environment. The impact of pollutants, hazardous substances, and noise on people's health is sizeable. Environmental quality also matters intrinsically, as most people value the beauty and healthiness of the place where they live and care about the degradation of the planet and the depletion of its natural resources (Durand, 2015). Families of CWDs prioritize sufficiently endowed public services to meet the needs of their children (Araújo et al., 2016). Čagran, Schmidt & Brown (2011) verified that despite all Slovenian families get the support of school services (special education, day programs, pediatric aid), more than half of the families in their study indicate that they do not receive the help they need. The most common obstacles that families found were related to transportation, waiting lists, difficulties on the access to services, discourteous treatment by professionals and lack of information about where to find local support programs (Čagran, Schmidt & Brown, 2011). The parents expressed that of transport is a challenge, they said their children were unable to go for a long-distance when it is time to take them to school or to the clinic, they face more problems (Thwala, 2015).

WHO (2004) study suggests an overall average of environment domain to be 13.5 out of 20. Netherland scored the highest QoL in this domain with 15.9, while the least score was 10.7 for Argentina. Environment domain scored 13.1 in Australia, 12.9 in Brazil, 14.8 in Bulgaria, 13.2 in China, 14.3 in Croatia, 13 in Germany, 11.9 in Greece, 13.6 in Hungary, 12 in India, 12.6 in Israel, 14.3 in Italy, 12.4 in Japan, 13.5 in Malaysia, 12.8 in Nigeria, 13.8 in Norway, 12.7 in Romania, 15.7 in Russia, 12.4 in Spain, 13.2 in Turkey, 14.1 in UK, and 11.7 in the US (WHO, 2004). Kareem & Ali (2014) from Iraq pointed out that in their study the environmental domain had scored the least domain among all domains which was in mothers of autistic children 34.73%.

In the GS, the situation of the environment domain and its subdomains is difficult and getting worse, in the report of "Gaza 2020 is A livable place?", the daily lives of Gazans in 2020 will be worse than they are now. There will be virtually no reliable access to sources of safe drinking water, standards of healthcare and education will have continued to decline, and the vision of affordable and reliable electricity for all will have become a distant memory for most. The already high number of poor, marginalized and food-insecure people depending on assistance will not have changed, and in all likelihood will have increased (UNSCO, 2012).

2.2.3.2 Parental stress index

Parental stress in its simplest definition is the experience of distress or discomfort that results from demands associated with the role of parenting (Hayes & Watson, 2013). The PSI was originally developed by Abidin (1983) and has undergone several revisions with the most recent published in 1995 (PSI-3; Abidin, 1995). It is a parent self-report questionnaire and is available in a long form or a short form. According to the developer, the PSI was intended as a screening instrument used to identify parent-child systems at risk for dysfunction (Loyd & Abidin, 1985). Both the short and long forms ask parents to read a statement and answer based on a 5-point Likert-scale. PSI provides three subscales; Parental Distress (PD), Parent-Child Dysfunctional Interaction (P-CDI), and Difficult Child (DC) (Abidin, 1995). According to the author, they have frequently been used with parents of children with disabilities or chronic illnesses of any age (Hayes & Watson, 2013).

The burden of caregiving imposed by the CWDs can have repercussions on the caregivers, for example, studies have indicated that, in general, the parents of children with CP perceive their own health as unsatisfactory, including symptoms of depression, stress, muscle pain, and diminished QoL (Lima, Cardoso & Silva, 2016). Another study was conducted on parents of children with heart disease who were more likely than the normative population to report excessive parenting stress, especially related to characteristics of the child that make them difficult to the parent (Uzark & Jones, 2003). Approximately 1 in 5 parents expressed clinically significant levels of stress (Uzark & Jones, 2003).

When parental stress is at high levels, it is associated with impaired mental health, poorer QoL and dissatisfaction with the social support perceived by the parents or primary caregivers of children with CP (Al-Gamal & Long, 2013).In Arab countries a cross-

sectional study that investigated psychological distress and perceived support among Jordanian parents living with a child with CP, revealed that more than 60% of parents often felt nervous and stressed (Al-Gamal & Long, 2013). Another study was conducted on Jordanian parents of children with Autistic disorder, which resulted in that those parents experienced significant high levels of parental stress and reported to have poor QoL in all domains especially mothers who reported a relatively lower score (Dardas, 2014).

2.2.3.2.1 Parental Distress

The PD subscale assesses the parent's stress arising from the parental role (Roccella et al., 2019). In a study conducted in Malaysia to investigate parental stress and parental ratings of behavioral problems of enuretic children, the total PD scored 22.36 out of 60 which equals 37.2% and in the same study the total stress mean was 93.41which equals 51.8% (Roccella et al., 2019). The results showed that parents of primary monosymptomatic nocturnal enuresis (PMNE) children showed significantly higher stress levels than parents of the typical developmental child (Roccella et.al, 2019).

Roccella et.al (2019) had studied parental stress and social support of caregivers of children with CP where PSI was used, it was found that most of the participants had high parental stress. Going with Roccella et.al study (2019), a study of parental stress and social support of caregivers of children with CP was conducted in eastern Amazon, where PD had the second-highest proportion of participants classified as having clinical Stress (33%). Regarding Arab studies, a study of stress, coping strategies, and QoL among Jordanian parents of children with autistic disorder was conducted and studied the PSI and its domain associated with QoL and other variables, it resulted that there was high level of stress experienced by those parents where PD score was (40.29 out of 60;67.15%) which is relatively high (Dardas, 2014).

2.2.3.2.2 Parent-Child Dysfunctional Interaction

The P-CID subscale evaluates the stress that derives specifically from the interaction with the child (Roccella et al., 2019). P-CDI investigates whether the parents' perceptions of their child agree with their expectations, in addition to whether their interactions with their child reinforce their role as parents (Lima, Cardoso & Silva, 2016). In Lima, Cardoso & Silva's (2016) study P-CDI domain showed to be the main source of stress where 45% of the participants were classified as having clinical stress. This domain concerns the caregivers' expectations for the child to meet the idealized image of him/her that they have

built (Ribeiro et al., 2014). Consequently, it might be assumed that the more the discrepancy is between the child's skills perceived by the caregiver and those that the caregiver would like the child to have, the more the difficulty of the caregiver to accept the child's disability (Lima, Cardoso & Silva, 2016).

The high scores on the P-CDI scale for the parents in (Dardas, 2014) indicated a sense of disappointment and dissatisfaction with their interactions with their children. Abidin (1995) stated that parents who report high score on this scale should be supported by giving them information to enhance their competence and confidence in their ability to build and bond intimate and strong relationship with their child. Deater- Deckard (2004) presented the bi-directional effects of both the child on the parent and parent on the child. For instance, if a child's behavioral emotional and difficulties increase over time, parenting stress is likely to increase. At the same time, the difficulties that parents face by themselves in mental health functioning can lead to problems which can increase levels of parenting stress.

2.2.3.2.3 Difficult Child

The DC subscale measures the stress that comes from managing a child that appears more problematic than the parent expected (Roccella et al., 2019). DC domain concerns several behavioral aspects of children that define them as easy or difficult to handle (Lima, Cardoso & Silva, 2016). Lima, Cardoso & Silva (2016) stated that among the three-domain DC was the least where 22% of participants were classified as having clinical stress. Moreover, Lima, Cardoso & Silva (2016) stated that the problems of a child's intellectual, emotional, and behavioral difficulties further increase the burden of caregivers and may influence their QoL and health negatively. As stated in Al-Gamal & Long study (2013) which studied the psychological distress and perceived support among Jordanian parents living with a child with CP, that adding to the behavioral problems, the presence of pain and sensory impairments in the child were also associated with a higher risk of clinical stress among parents of children with CP. Similar to the findings of Lima, Cardoso & Silva (2016) study where the presence of health problems in the children influences the occurrence of clinical stress among the caregivers. Another study in Jordan on Autistic children parents revealed high scores on the which reflected how difficult the parents perceive their children, those parents were expected to benefit greatly from strategies aimed at handling challenging behaviors (Dardas, 2014).

Many studies revealed that there is a strong association between parenting stress and problematic child development (Richardson, 2010). In general, parents of CWDs, particularly disabilities that result in increased behavioral issues, have been found to have increased levels of stress (Richardson, 2010).

2.2.4 Caregiver's demographic characteristics

Caregivers frequently exhibit burden, and its intensity depends on several factors, one of them is caregiver characteristics, from a demographic standpoint (i.e. gender, occupation, educational level) (Carod-Artal et al., 2009). In a study on the prevalence of caregiver burden of CWDs, the majority of the caregivers are suffering from all types of burden including financial burden, social problems, etc., because most of them were uneducated people and they have low-income levels (Darsana & Suresh, 2017). A systematic review of 18 studies showed that there is a significant relationship attributed to higher caregiver burden and the overall QoL of caregivers in relation to the patient's level of performance, age, and gender (Datta & Kar, 2016). As evident in the study eight out of the 18 articles observed the relationship between caregiver characteristics and their QoL, characteristics such as caregiver's gender, caregiver's age, physical disability, family income, level of education, where deteriorating health, anxiety, depression, and anger were addressed (Datta & Kar, 2016). Eight out of the eighteen articles studied the association between a caregiver's age and QoL, and five studies reported a greater correlation with an age above 50 (Datta & Kar, 2016). While studying the relationship between a caregiver's gender and QoL, three of six articles showed that females were more prone to depression (Datta & Kar, 2016).

Caregivers who were older, female, in a spousal relationship or were co-residents experienced significantly higher caregiver burden than caregivers who were young, non-spousal and non-resident caregivers (Kim et al., 2012). Another study in Kenya highlighted the variation between family types among caregivers and stated that in the past the extended family would be available to provide care to an ID child easing the burden of care expected from the nuclear family, however, in recent times there is a shift from extended family to nuclear family (Mbugua et al., 2011).

2.2.5 Child individual characteristics

CWDs characteristics including gender, age, education and nature of disability were varied and some studies confirmed the contribution of them to more burden, and others found them not significant to make a difference. A systematic review of eighteen studies which assessed QoL burden on caregivers of chronically ill patients revealed that patient characteristics that had significantly attributed to higher caregiver burden and the overall QoL of caregivers were the patient's level of performance, age, gender, anxiety/depression and the type and severity of illness (Datta & Kar, 2016). Also, Datta & Kar (2016) added that although patient characteristics such as age, gender were considered, they did not seem instrumental in changing the dynamics of burden.

In a study in South Korea on children with developmental disabilities, the child age was reversely associated with LS of the caregivers (Cho & Kahng, 2014). Furthermore, as for the ADL, nearly half of caregivers of children with special needs (47%) help the child with at least one ADL (National Alliance of caregiving, 2009), where mothers are more active in their child's care and bear most of the burden associated with it. They tend to give themselves little time to adjust, as the CWD continues to require ongoing care. Mainly mothers have difficulty with child caretaking, difficulty of feeding, bathing and dressing and caretaking time (Kerenhappachu & Sridevi, 2014). Regarding the nature of disability, a number of studies have investigated whether the type of disability has an impact on caregivers QoL. Studies have shown higher depression scores among caregivers of an autistic child when compared to caregivers of a child with an ID without autism (Mungo et al., 2007). Lower QoL was reported by Mungo et al. (2007) for parents of children with a pervasive developmental disorder when compared to parents of children with an ID, CP and non-disabled children. In Gaza, a survey was conducted to address and understand the needs and perspectives of CWDs, it revealed that there were differences among different types of disabilities in the difficulties faced in accessing services (Jones et al., 2016).

An evidence-based systematic review assessed the burden on caregivers of chronically ill patients reported a significant relationship between the type of illness of the recipient and the burden of caring (Datta & Kar, 2016). Savage & Bailey (2004) mentioned in their study that some aspects of the impact of caregiving on the caregiver's mental health differ depending on the nature of the care recipient's disability, for example, caring for a person with mental illness may involve a degree of uncertainty for the caregiver, a lack of control for the caregiver and manipulation by the care recipient. As evident from research, there is

a close relationship between the duration and severity of disease with that of QoL of informal caregivers, moreover, there have been instances where in order to meet the needs of the patient living in the family subjects have changed their habits (Ferrara et al., 2008).
Results of a study on the burden of caregiver showed that both the burden and the QoL are significantly worse for caregivers who care for patients with both physical and mental diseases. Caregivers most disadvantaged are those who indicate as a reason for care the sense of duty rather than affection (Settineri et al., 2014).

2.2.6 Service provision

Caregiving is a crucial service in societies, often offered without pay, it preserves the health of disabled or aging citizens. State health systems would be unable to provide adequate coverage to the disabled without caregiver contributions (Talley & Crews, 2012). Caregivers reported challenges with accessing social assistance grants, health-care services, educational and recreational facilities, and other public infrastructure (Mathye & Eksteen, 2016). To add to this, insufficient transportation and affordable housing, alongside poverty in a rural, made caregiving more difficult (Mathye & Eksteen, 2016). Some caregivers felt they lacked sufficient professional support in looking after their children (Mathye & Eksteen, 2016). They also spoke about how sometimes the clinic did not have stock of the drugs prescribed for their ill relative. Others reported that a lack of equipment and materials for proper care of CWDs was one of the challenges experienced by caregivers. (Mathye & Eksteen, 2016).
According to Jones et al. survey (2016), Palestinian caregivers of CWDs and their CWDs were underserved by mainstream public services such as education, health care, psychosocial support, and rehabilitation—leaving more than three-quarters of Palestinian families with CWDs reporting it to be ‘very difficult’ to make ends meet because of costs related to disability (71.6% in Gaza). 45.3% of surveyed HHs reported that it was very difficult to obtain assistive devices, 42.8% found it very difficult to obtain rehabilitation services and 23.6% considered it very difficult to stay in school. To sum up, on average, Palestinian families with CWDs reported that they experienced a ‘high’ level of difficulty in accessing basic public services (Jones et.al, 2016).
Lack of knowledge is also an important factor for the burden on a caregiver (Darsana & Suresh, 2017). USA caregivers of CWDs when asked where they would turn for information related to caregiving, nearly four in ten caregivers of children with special needs would seek out a health provider (38%), another one in four that they would turn to

the internet (24%), while two in ten would rely on family, friends, and other caregivers (22%) (National Alliance of caregiving, 2009). In a study of caregiving burden among CP children, it was mentioned that measuring levels of knowledge and understanding about CP were not a component of the QoL measure in (Zuurmond et al., 2015), but the qualitative data highlighted low levels of understanding about CP, common myths held, and provides some explanation of the stigma felt by caregivers (Zuurmond et al., 2015). Many caregivers in South African studies felt they lacked sufficient skills for caring for their CWDs (Mathye & Eksteen, 2016). Caregivers of CWDs in a number of South African studies felt that they did not have enough information about their care recipients 'disabilities, rehabilitation, and care needs (Mathye & Eksteen, 2016).

2.2.7 Difficulties faced by caregiver related to child disability

The need for special care varies among CWDs, some need medical care, others need educational care, some need extreme help in ADL, others need psychological care etc. Although patient characteristics such as age, gender were considered, they did not seem instrumental in changing the dynamics of burden (Datta & Kar, 2016). Regarding education needs, boys and girls are equally likely to be out of school (37.8% versus 37.4%) however, preschoolers and secondary-aged children are far more likely to be out of school than primary-aged children (30.2% versus 62.7% and 48.5%, respectively). This is primarily because pre-school in Palestine is provided almost entirely by NGOs—many of which do not accept CWDs at all—and older students typically require far more adaptions in order to be academically successful, given the more strenuous content they are expected to master (Joes et al., 2016). The previous example is to point out the special need that is related to disability that may constitute a burden on the child caregiver regarding education. In addition to the general challenge and pressure of raising a CWD, other factors are also linked to caregiving burden. For example, the education of CWD is associated with the level of psychological stress (Al- Krenawi, Graham & Al Gharaibeh, 2011). Furthermore, several issues related to the preparation of education personnel to present challenges to effective inclusion. Some families may be concerned for their child's safety in settings where the staff is not specialized in a specific disability or the special needs of their child (Al- Krenawi, Graham & Al Gharaibeh, 2011).

Parents of CWDs have to deal with complex issues related to the child's education (Smith, English & Vasek, 2002). Either a private education must be sought or an adequate public or general education must be available. Close parental contact with the school system is

vital in order for the child to receive a proper education (Smith, English & Vasek, 2002). Parents must collaborate with teachers in order for their child's education to be effective (Smith, English & Vasek, 2002). Teachers and parents have to be partners in the education of the child with a disability (Smith, English & Vasek, 2002). In Palestine, as Jones et al. (2016) stated nearly 38% of children were out of school entirely and less than 45% are enrolled in regular education. Added to more than one-third of CWDs reported that disability limited their access to education with only about a quarter feeling their school was supportive of CWDs and a third saying educational tools were not adapted to their needs (Jones et al., 2016).

Importantly, ADL is part of caregiving where mothers are the primary caregivers for nearly 60% of CWDs in Gaza and complementary care, which is most often provided by fathers and sisters (25%) (Jones et al., 2016). ADL is an important side of the disability-related difficulties where according to the National Alliance of caregiving (2009) in the U.S, nearly half of caregivers of children with special needs (47%) help the child with at least one ADL. The performance of ADL is less common for caregivers of children than it is for caregivers caring for an adult (58% help with at least one ADL). The ADLs most commonly performed for children are grooming tasks: getting dressed (35%) and bathing or showering (28%) (National Alliance of caregiving, 2009). Most CWDs according to Jones et al. (2016) do not experience significant difficulty with ADL such as dressing themselves and toileting but there was a significant difference in difficulties faced in ADL according to the type of disability where the physical mobility disability was the highest to face difficulties (Jones et al., 2016). On the other hand, over 20% are completely unable to bathe themselves and nearly 18% are completely unable to dress and nearly 15% to move about outside of their own homes (Jones et al., 2016). Similarly, in another study conducted in Palestine where mothers felt alone and in satisfying the child's daily care such as hygiene and schooling and accepted that the father's main role was to meet the economic needs of the family, but they expected him to be there at some points, namely, when psychosocial difficulties arose (Nahal et al., 2017).

Rather special care like intermittent hospitalization, emergency room visits and medications have exerted a significant burden. "*In all cases, after those hospitalizations, the family caregivers took on added responsibilities for assisting with ADL, such as bathing and feeding, and instrumental ADL, such as shopping, managing the HH finances, and taking care of the children"* (Schubart, Kinzie & Farace, 2008 P:66)**.** There is an association between the number of medicines and injections taken by the child per week

and the mother's burden which may suggest that mothers are very involved in helping their children obtain or remember their medicines (Javalkar et al., 2017). The association between emergency room visits and burden may be because a higher number of health emergencies can contribute to stress and anxiety (Javalkar et al., 2017).

As for health needs for CWDs in Palestine, 26.9% want access to specialized medical care for their CWD but are unable to obtain and 26% of HHs would like access to speech and language therapy. Over 90% of families pay for them out of pocket and over 16% of children with mobility-related disabilities who need a powered wheelchair do not have one and over a third of hard-of-hearing children lack hearing aids (Joes et al., 2016).

With regard to health-related difficulties, Talley & Crews (2012) indicated that caregivers require supportive services for their caregiving tasks and good health status is needed to provide better care for the needy. While another study mentioned that shifting the rehabilitation services from child-centered to family-centered services by providing supportive services is recommended (Al-Kuwari, 2007). When a CWD receives professional health care, the needs of the child are generally the focus rather than on how parents are coping with the situation. Consequently, if the family as a unit is the focus of care and support, caregiver burden can be relieved, especially during those difficult experiences when a child may be hospitalized or receiving therapy (Darsana & Suresh, 2017). Parents also report increased burden when there are few resources available to help them find good healthcare and support for their child (Darsana & Suresh, 2017).

Furthermore, in relation to Palestinian health-related difficulties, the Jones et al. (2016) survey found that CWDs' lack of access to health care had significant implications for their QoL. They were asked to determine the number of days that they had felt well versus unwell, the average Palestinian CWD reported feeling unwell in terms of their physical health for 5.6 days of the previous month and their psychosocial/mental health for 6.6 days (Jones et al., 2016). All the previous have its reflections on caregiver in terms of difficulties faced such as lack of access to health.

2.2.8 Cultural norms

Culture has implications for how families define and experience disability, how families experience their interactions with the formal service system, and how parental child-rearing values develop (Neely-Barnes & Dia, 2008). Dominant cultural norms sometimes form a burden; for example in a study for understanding the lives of caregivers of children with CP in rural Bangladesh, the low levels of understanding about CP was highlighted,

common myths held, and provides some explanation of the stigma felt by caregivers where parents commonly held several concurrent beliefs regarding the cause of their child's condition (Zuurmond et al., 2015). The most common beliefs were that it was caused by bad spirits and/or the result of something they did or that happened to them during pregnancy. Despite several reported visits to healthcare providers, most families had not received any diagnosis for their child (Zuurmond et al., 2015).

Parents mentioned visits to traditional healers for treatment of their child's condition and described having been to different types of traditional healers in their endless search for a cure for their child (Zuurmond et al., 2015). Moreover, Zuurmond et al. (2015) reported under the theme of family support, some caregivers described individual members of the family and neighbors who loved their child that they were sympathetic and caring. However, the overall key themes were in isolation and lack of support; the difficulty in talking about their child's condition within the family, which was often compounded by the high levels of stigma surrounding having a child with a disability (Zuurmond et al., 2015). As for perceptions about disability, once a child is identified as having an ID, family members may anticipate discrimination through awareness of stereotypes (e.g. that other people will believe that family members are culpable in the genesis of the child's condition). Accordingly, two harmful ways that families may respond to anticipated rejection are secrecy or hiding the condition, and withdrawal from social activities. This model is particularly relevant to understand stigma in Asia, where secrecy is used as a predominant coping mechanism and has impacted upon social recovery and reintegration (Ngo et al., 2012). In the same study on caregivers of children with ID stated that due to widespread discrimination toward ID in Asia, the stigma might place unfair restrictions on the social life of these individuals and their primary caregivers. Studies of stigma among families of children with ID have focused on the resulting caregiver burden among caregivers (Ngo et al., 2012). For example, studies in the west have indicated that stigma has predicted increased subjective burden QoL, social isolation and depression among caregivers. Studies of caregiver stigma in Asia also showed culture-specific findings (Ngo et al., 2012). Hassall, Rose & McDonald (2005) conducted a study to find out the effect of family support - formal and informal (social) on coping with the psychological pressures faced by families and used PSI and a scale for family support, The results of the study pointed to the impact of family support, in particular, form social support in reducing the level of psychological pressure.

In Arab countries like Jordan, Domra & Mahmoud (2016) had resulted that the level of support for families of CWDs were generally in moderate average, as well as for all families of CWDs in mental disabilities, autism, and hearing, while the level of support was low for families of physically disabilities, and families of visually impaired children.
According to Jones et al. (2016), the stigma surrounding disability in Palestine is both pervasive and strong (Jones et al., 2016). It resulted that mothers were almost universally supportive of their CWDs, fathers and siblings are less and outside the HH there was very little support (Jones et al., 2016). Additionally, Nahal et al. (2017) revealed in their qualitative study that the health care providers seldom recognize the mother's needs for emotional support at the time of diagnosis and crisis. These unexpected reactions of the health care providers made it more difficult for the mothers to understand what was going on, however, when help and support from health care professionals was received, it was highly valued by the mothers, positively affected their outlook, and increased their hope.
It is worth talking about discrimination when we talk about disability where about one in four Palestinian CWDs reported that they felt the always community discriminated against CWDs. About 30% reported that they avoided doing things that they could do simply because of other people's attitudes towards them. CWDs are frequently subject to name-calling—usually from other children in the community or in their extended family (Jones et al., 2016).

2.2.9 Forgone opportunities

Many opportunities are lost for caregivers due to what caregiving takes of time and effort and even stress. One of the lost opportunities is education, most of the studies focused on the consequences of caring on work and social capita, however education of the caregiver was included in the demographics. It is noticed in the study of caregivers in the USA, caregivers of children with special needs tend to be less educated and have lower HH income than caregivers of adults (National Alliance of caregiving, 2009). One-third of caregivers of children had no more than a high school education and a similar proportion have completed college (National Alliance of caregiving, 2009). Spending a lot of time with the child makes studying opportunity is very difficult for the caregiver. While in Gaza only 40.3% of the mothers are with secondary school and above and 45.1% are the fathers (Jones et al., 2016).

Another area that might be lost is work, it is often reported that caregivers of individuals with disabilities experience stress as they manage caregiving responsibilities while they make the effort to balance family and work (Raver & Michalek, 2011). Financial stability/security appeared elusive to many of the respondents in a study of Gains and losses (2011), the majority of caregivers indicated that present financial supports provided to families in the United States were inadequate (Raver & Michalek, 2011). Emerson (2003) indicated that often mothers reduce the number of hours they work or leave jobs to provide care for a CWD. In this study, the desire to find or keep a job that met the family's needs was repeatedly indicated as an urgent need by the respondents. Three out of four caregivers of children reported making changes to their work situation (National Alliance of caregiving, 2009). Those who are caring for a child are three times as likely as those caring for an adult to have had some of the more severe impacts on their employment situation, cutting hours or taking a less demanding job, giving up work entirely, and losing benefits. They are also more likely to have taken a leave of absence (National Alliance of caregiving, 2009).

It is worth mentioning the impact related to social capita, where some studies like Grover & Dutt (2011) showed that parents of children with Down's syndrome spent more time in child care, and they have less recreational time and social activities in comparison to parents without a disorder. Greater burden and lower QoL were predicted by three fundamental parameters: duration and severity of illness decreased tangible social support with restriction of caregiver social life and negative feelings of caregiver such as shame, embarrassment, guilt and self-blame (Grover & Dutt, 2011). While research has focused on the impacts on caregiver burden, the potentially major role of stigma in the restriction of the social life of caregivers has been neglected. Data on how such a restriction on social life occurs might improve both the isolation and depressive symptoms (Ngo et al., 2012). While the quantitative findings of Ngo et al. (2012) study documented the effect of the child's ID on limiting caregivers' social experiences, the qualitative analyses illustrated key features of how these negative social life concerns and experiences are manifested (Ngo et al., 2012).

From Egypt, Darwish (2013) stated in her study on the QoL of parents of Autistic children that the family begins to pay more attention to the child due to additional requirements such as saving more time to observe and the behavior of the child and the fear of not being aware of the risks around him and may affect family ties and relationships with other families due to child preoccupation. While from Iraq a study was also conducted on the

same subject indicated that mothers had a lower mean for all domains and items of QoL in comparison to their partners. This possibility likely reflected the general self-esteem of women and their position and responsibility in Arab society. There was also the risk that staying at home most of the time to support a child who had autism could increase the psychological pressure experienced by mothers due to possible job loss and limited support from the community and health sectors, which would likely resulted in a lower mean in the QoL (Kareem & Ali, 2014).

2.2.10 Financial burden

Disability and poverty have a bidirectional relationship; meaning that disability is a cause and a consequence of poverty (Pinilla-Roncancio, 2015). Low levels of nutrition, limited access to preventive health care, low access to sanitation and clean water and violence are some factors that increase the risk of becoming chronically ill for poor populations (Pinilla-Roncancio, 2015). On the other hand, people with impairments face extra costs and barriers in their access to health care services, including rehabilitation and technical aids; they are socially excluded from education and employment and have to assume direct, indirect and opportunity costs, which negatively affect their income and consumption (Pinilla-Roncancio, 2015).

A study on caregivers of Autism children showed that caregivers with ASD children were more likely to be in substantially lower income HHs, and to have costly educational expenses (Al-Dujaili & Al-Mossawy, 2017). Therefore, the HH income was decreased in families with ASD children, because of the parental training and education and healthcare services for ASD and was positively associated with family income (Al-Dujaili & Al-Mossawy, 2017). As one of the most important aspects of burden, is financial one; supported employed programs and lifelong financial help should be planned not only for the autistic children but also for the families (Al-Dujaili & Al-Mossawy, 2017). Al-Dujaili & Al-Mossawy (2017) suggested that those caregivers of ASD were more likely to be in substantially lower income HHs and to have costly expenses. Therefore, the HH income was decreased in families with ASD children. The financial strain of the child's condition and the caregiver's ability to hold a job is a significant factor in determining the caregiver's QoL. The financial strain of the child's illness significantly impacted the caregiver's QoL in studies that examined financial stressors (Spore, 2012). As National alliance for caregiving (2009) stated that caregivers of children are more likely to feel at least some financial hardship as a result of caring for their loved one than their

counterparts who care for an adult, and twice as likely to feel strong financial hardship. One in three of caregivers of children has sought financial assistance on behalf of the child (32%). Nahal et al. (2017) conducted a qualitative study that concentrated on mothers and the impact of caregiving of child with spina bifida on them and shed alight on the economical burden faced where burdensome responsibilities were considered essential to ease the child's life, for example, this sometimes necessitated moving the family to a ground floor, renovating the home, or changing residential area.

2.2.11 Psychosocial burden

It is well-documented that CWDs are often socially excluded, and frequently lack access to primary and rehabilitative healthcare and education (Jones et al., 2016). In addition to the cultural stigma that is adherent to disability, discrimination according to gender and type of disability are also founded in the community. Parents raising a child with a special health need often report insufficient supports and feelings of helplessness (Smith & Grzywacz, 2014). In another study that concentrated on stigma and restriction on the social life of families of children with ID in Vietnam, it was found that widespread discrimination against ID in Asia may initiate stigma that places unfair restrictions on the social life of these individuals and their caregivers (Ngo et al., 2012).

Caregivers reported elevated levels of social exclusion. As hypothesized, parents of children with greater ID experienced more restrictions on their social life (Ngo et al., 2012). In the study of Ngo et al. (2012), there was a demonstration of how some Asian countries perceive stigma of disability according to culture, for example, stigma may be associated with cultural dynamics indicating 'loss of face' (in Hong Kong) or being labeled by the community as an 'unsuccessful family' (in Taiwan). While research had focused on the impacts on caregiver burden, the major role of stigma in social life restriction of caregivers had been neglected. (Ngo et al., 2012). In Palestine Nahal et al. (2017) study revealed that emotional impacts on mothers of children with spina bifida were pervasive including feelings of fear, worrires, blame and guilt, uncertainty and social isolation.

2.2.12 Time use

The distinction of given day-to-day variation in how people spend their time is analytically important. Frazis & Stewart (2012) examined the conditions necessary to make inferences about the time use of individuals from a sample of person-days (Frazis & Stewart, 2012).

An important contribution of the time use survey is that it gives detailed information to provide a complete picture of how people spend their days (all 24 hours) on different economic and non-economic activities. So it is in fact, the only available survey technique to us at present that provides a comprehensive information on how individuals spend their time, on a daily or weekly basis, and "reveals the details of an individual's daily life with a combination of specificity and comprehensiveness not achieved in any other social survey (Hirway, 2000). They were designed to assess progress in lifestyles, focusing on time spent on leisure, and on transport and commuting, and also to compare paid and unpaid work (Charmes, 2015).

As for time use for caregivers, a study was conducted on parents raising children with severe or profound intellectual and multiple disabilities (PIMD), the study resulted in that there were significant differences between the parents of children with PIMD and the parents of typically developing children in terms of committed time (time for domestic work and the care and supervision of their children) and free time. The mothers of children with PIMD spend significantly less time on domestic work and more time on care and supervision than mothers of typically developing children (Luijkx, Van der Putten & Vlaskamp, 2017). The study concluded that a significant amount of time has to be spent by parents on care and have an average 1.5 less free time per day than parents of typical children, and referred that this conclusion is striking because of the important contribution of leisure time to wellbeing (Luijkx, Van der Putten & Vlaskamp, 2017). The national alliance for caregiving (2009), had reported the hours spent with ADL and supportive activities, where caregivers of CWDs had a more intensive experience than adult caregivers were on average 29.7 per week; based on the hours they spend helping with the ADLs and supportive activities caregivers of children with special needs have a more intensive caregiving experience than caregivers of adults. On average, caregivers of children spend 29.7 hours per week providing care, nearly 18 hours more per week. One in four provides care for at least 41 hours a week (24%).

Another study was made to compare the time use of mothers of CWDs with the time use of mothers of children without disabilities which resulted in there were significant differences found between groups when mean hours spent per week by mothers in occupations involving child-care activities and recreational activities were compared and as stated before CWD mothers spent significantly more time in child-care activities and significantly less time in recreational activities. In addition, CWDs mothers reported fewer typical days and rated the quality of days as poorer (Crowe & Florez, 2006).

In Palestine, time survey was done twice in 2000 and 2013 for both men and women where the activities were distributed on 24 hours a day as a percent, where the average Palestinian woman and man spend on most of their day on personal care and maintenance; including religious activities and rest and sleep. Women spend 52% and men 55% on personal care and maintenance, while social life and leisure consumes 20% of women time and 35% of men's, learning takes 8% of women's time and 7% of men's, unpaid work takes 20% of women's time and only 9% of men's and finally the paid work consumes 2% of women's time and 12% of men (Charmes, 2015).

Chapter Three

Methodology

This chapter presents the methods used in this study. It describes the design of the study, the sample selection and sampling methods and process, how data was collected and analyzed. Moreover, a description of the piloting process is provided, in addition to the period of the study and the response rate. Information about the study instruments, its reliability and validity are disclosed in addition to the study limitations.

3.1 Study design

This study adopted a mixed-method design, combining both, quantitative and qualitative methods. It is a descriptive, analytic, cross-sectional one. Cross-sectional studies reflect the existing facts at the same point in time of data collection, adding to being less expensive and less time consuming than other longitudinal studies (Setia, 2016). In this study, methodological triangulation provided a combination of quantitative which gives solid numerical values (interviewed questionnaire with clients) and qualitative paradigm which gives in-depth understanding (in-depth interviews with key service providers and focus groups (FGDs) with caregivers of CWDs and their other family members). The mix of methods allows for validating findings from one method with another or to enhance understanding of the facts on the ground (Donovan & Sanders, 2005).

3.2 Study population

Two populations were included in the study:

3.2.1 Quantitative part:

Main caregivers who were mostly the mothers, followed by fathers, siblings who provided practical, day-to-day unpaid support for a person unable to complete all of the ADL. According to the available data, the number of CWDs is 14, 244 (Jones et al., 2016).

3.2.2 Qualitative part:

The first population was family members of the 14,244 CWDs including fathers and mothers. With them, the researcher conducted 7 FGDs.

The second population was the key informants/decision-makers and experts in different fields and associations related to disability including service providers, with whom the researcher conducted 11 Key Informant Interviews (KIIs).
The third population was the siblings who lived with the CWDs including brothers and sisters where the researcher conducted with them 6 In-depth Interviews (IDIs).

3.3 Study setting

Quantitative data was collected at the HH level. While the qualitative part was conducted in facilities serving CWDs and community-based organizations in GS. As for KII, these were conducted in the offices of the key informants in the different associations they work at their convince.

3.4 Eligibility criteria

3.4.1 Quantitative part:

3.4.1.1 Inclusion:

The caregivers who were included:

- Females or males who had a CWDs or more than one CWDs.
- CWD is registered in the database of MOSD or NGOs
- Unpaid for caregiving as a job during the data collection period.

3.4.1.2 Exclusion:

- Paid caregiver for CWDs whose job is caregiving.
- All who don't meet eligibility inclusion criteria.
- CWDs are not known or registered at any organization.

3.4.2 Qualitative part:

3.4.2.1 Inclusion:

- To be an unpaid caregiver of CWDs during the data collection period.
- To be a key informant in service provision for disability-related fields.
- To be a sister or a brother for CWDs.

3.4.2.2 Exclusion:

- Paid caregiver for CWDs and all who don't meet eligibility inclusion criteria.

- A key informant not related to the field of disability.
- Someone not related to the CWDs.

3.5 Study period

The study consumed around 16 months; it started in July 2018 and was completed in September 2019. Annex (1) describes the activities of the research and the expected duration for each activity.

3.6 Sample and sampling

3.6.1 Sample calculation

3.6.1.1 Quantitative

According to (PCBS, 2012) 12,127 CWDs were in GS but the data was updated to cover the newly CWDs caregivers to include CWDs who were not in the 2012 survey and the CWDs number was 14,244 (Jones et.al, 2016). The researcher used the Epi-Info sample size statistical calculator using the following parameters; Annex (2):

- 95% confidence level.
- 5 % acceptable marginal error.
- Study population 14244.
- The sample size suggested equals 374.
- The researcher increased the sample up to 400 individuals among those presented to compensate non-respondents.

3.6.2 Sampling process

3.6.2.1 Quantitative part

A stratified systematic random sample (multi-stage) approach was followed; done on four stages. First, GS areas were divided into five areas (clusters) for distribution of the study sample geographically across the five governorates of the GS (North, Gaza, Middle, Khanyoinis, and Rafah) then by gender of the CWDs, also by the type of disability and lastly age of CWDs, 2016 children disability data was updated to cover 2016, 2017.

3.6.2.2 Qualitative part

KII sampling was conducted by selecting a non-probability purposive sample of 10 key informants. The idea of including this sample was to dig deep and understand in-depth the perspectives about caregivers' challenges. The researcher paid attention to the types of disability and governorate representation to enhance data triangulation. The qualitative component was carried out after the quantitative one in order to explore issues that emerge from the quantitative study. As for brothers and sisters, also they were purposively selected to be interviewed to present the deep challenges from inside the family from other family members' perspectives and present a complete picture (see Table 3.1).

3.7 Study instruments

This study utilized various instruments which are clarified in Table (3.1) and detailed in Annexes (3), (4), (5), (6), (7).

Table (3.1): Illustration of the various instruments used in the study

Tool	Number	Description
Questionnaire	400	Factors affecting, services QoL and PSI and challenges (see annex 3).
FGDs with mothers of CWDs	5	7 -10 participants in each discussed the aspects of the QoL, PSI, satisfaction level, impact of having a CWD. FGDs included mothers with different kinds of disabilities, different age cohorts, and different geographical areas. In total, 45 participated (Annex 4).
IDI with sisters of CWDs	3	The role, challenges, and dynamics, burden, forgone opportunities. (Annex 5).
IDI with brothers of CWD	3	The role, challenges, and dynamics, burden, forgone opportunities. (Annex 5).
FGDs with fathers of CWDs	2	8 -10 participants in each discussed the aspects of the QoL, PSI, satisfaction level, impact of having a CWD. FGDs included mothers with different kinds of disabilities, different age cohorts, and different geographical areas. In total, 18 participated (Annex 4).
KII	11	Policymakers, service providers at different levels, challenges, and solutions. (Annex 6,7).

Quantitative instrument:

An interviewed questionnaire consisted was used to collect the quantitative data (Annex 3 shows the English and Arabic versions). It has been constructed from the WHO wellbeing scale of 26 questions and PSI scale of 28 questions along with self-constructed questions for other areas of the study including the burden of caregiving process to search correlates. the main items covered in the questionnaire (Annex 3) were related to:

1. General information and demographic variables for the caregiver and the CWDs like age, education, employment, family size, family type.
2. Caregiver general views about his QoL, health, psychological status, social relationships, and environmental status.
3. PSI was to answer some distressing factors of caregiver like handling things very well, feeling trapped in responsibilities, feeling alone, not enjoying as used to be. Including its domains of PD which concentrates on how interaction happens between child and caregiver, P-CDI and DC where the focus is on the child behaviors like sleep and mood and problem making.
4. Disability-related factors such as type and reason of disability, degree of dependence, need of special care services.
5. Sociocultural challenges (stigma, relationships, people support)
6. Any consequences occurred as a result of the caring process and existence of CWD in the family. (forgone opportunities in work, education, social capita) and service provision challenges, financial burden.
7. Time use of caregiver during 24 hours and time spent with CWD by father and mother.

Qualitative instruments:

For the qualitative part, a semi-structured schedule (Annex 4, 5, 6) consisted of six-ten questions was designed based on the initial findings of the quantitative data.

The first tool is FGD with mothers and fathers, each FGD had 7-10 participants who were purposefully selected (Annex 4), the groups were encouraged to participate and give their opinion in interactive conversations that included domains like:

1. Satisfaction about life, how caregivers' life differs from others in relation to QoL.
2. The typical day, how it looked like, how they consumed time throughout the day.
3. Sorts of support (from government/ NGOs/ religious organizations) they received.

4. The burden faced: self-care and hygiene, education, transportation, health care, socialization, Psychosocial, transportation, costs of care, etc. The social support to them and its extent and levels.
5. The forgone opportunities for them and for the family that were attributed to disability
6. A letter to a responsive policymaker to address their challenges and needs.

The second tool is IDI (Annex 5) to cover some aspects like:

1. Satisfaction about life, how their life differs from others in relation to disability.
2. The typical day, how it looked like, how they consumed time throughout the day.
3. The care they provide for their brother or sister with a disability and what care they receive from parents.
4. The burden faced if they have difficulties in studying, recreational time, etc.
5. the forgone opportunities for them and for the family that was attributed to disability.
6. A letter to a responsive policymaker to address their challenges and needs.

The third tool is KII (Annex 6) to cover some aspects like:

1. About the organization's role for CWDs, the main focus. the services provided for families of CWDs especially the caregiver, the beneficiaries, targets, size of the program and feedback from them.
2. Social interactions and life in the community, treatment of families of CWDs and Community attitudes towards CWDs and their families.
3. The main barriers to the well-being of caregivers of CWDs to access and utilize basic social services and other critical resources. Challenges faced seeking services, costs, transportation, time. Stigma challenge and how could it be reduced.
4. Kind of support might be provided to caregivers.

3.8 Ethical and administrative considerations

An academic approval was taken from the School of Public Health at Al-Quds University. The Modified International Code of Ethics Principles (1975), known as the Declaration of Helsinki, which is adopted by the World Medical Assembly was followed and an official letter of approval to conduct the research was obtained from the Helsinki Committee-GS

(Annex 8). In accordance with the Principles of the Helsinki Ethical Declaration, every participant in the study had received a complete explanation of the research purposes, confidentiality, and sponsorship. To guarantee participants' rights, a covering letter indicated that participation is voluntary and confidentiality was assured for all of them. As for administrative approvals, they were taken from the visited organization serving CWDs (annexes 9,10). The key informants were asked for their permission to record the in-depth interviews. In this study, carefulness was exercised to ensure that the rights of the participants were protected. Every participant in the study had known that participation in the research is optional. Informed consent was obtained from the participants in the study. Additionally, formal permission for taking notes and tape recording of the FGDs was obtained. Last but not least, to increase the responses credibility, the researcher-maintained adherence to the Ethical Code Principles, through providing and maintaining anonymity and confidentiality. The researcher assumed that other ethical rights were protected through respect for people and respect for truth.

3.9 Pilot study

3.9.1 Quantitative part

A pilot study on 20 caregivers was done to explore the appropriateness of the study instruments and let the researcher train for data collection. Three questions were added and a few rephrasing or explanations were added to some other questions. Participants of the pilot were excluded.

3.9.2 Qualitative part

A pilot interview and a pilot FGD was done. This also allowed for further improvement of the study validity and reliability of the study.

3.10 Methods of data collection

3.10.1 Quantitative part

Following the piloting that was done jointly by the researcher and the data collectors, data collectors were in the fieldwork. There were five female data collectors who had experience in HH work in CPR, one from each governorate. Face-to-face interviews took place at the respondents' houses all over the GS as described. Prior to field trial and

piloting, data collectors had received ten training hours in a formal training setting. The training consisted of two parts; a refresher on sampling and picking targeted respondents and orientation on the study objectives, explaining key concepts, terms, and ideas of the questionnaire in order to unify the data collector's understanding, language, and method as a step for quality assurance. Around 7 hours were devoted to practical training that included role-play, and one to one interviews. In addition, a detailed instructions sheet was annexed to the questionnaires to guide the data collection process and to unify the way of presenting the study to respondents to obtain their voluntary consent. The required forms and templates were designed before starting the training so as to make sure data collectors become familiar with them prior to fieldwork. The respondent from each selected HH was interviewed for a duration ranged from 45 to 60 minutes (50 minutes on average). As instructed, data collectors were reminding respondents every five to seven minutes with the scale against which opinions were ranked. In addition to reading questions and answers, data collectors made printed versions of the questionnaire available to respondents during answering the multi-option questions. Privacy was maintained where respondents „freely" indicated their preferences especially when it came to satisfaction and social relationship. Generally, data collectors and the researcher respected and maintained confidentiality.

3.10.2 Qualitative part

The researcher had conducted 7 FGDs. Prolonged engagement and probing techniques were used to make sure ideas were reasonably reflected. The researcher had conduct 5 FGDs with mothers of children with different types of disabilities, 2 with fathers of mixed types in both groups, 3 IDI with sisters of multiple disabilities children, and 3 IDI with brothers of multiple disabilities children and they were conducted among GS added to 11 KII. Each FGD lasted for 90 minutes on average and had seven to ten participants with various characteristics. During FGDs, the researcher introduced the study objectives in a short while after the first question in order not to orient or influence the primer thoughts of the participants. The first question was made to explore initial thoughts/perspectives about wellbeing. To the possible extent, the researcher and the note-taker ensured that everyone's inputs were expressed and that gestures and tones were noticed. The researcher with the help of one person a note-taker had collected the data through open-ended (semi-structured) questions. Those questions were asked by the researcher within both the FGD with caregivers and fathers, as well as through the face to face in-depth KII. And short notes were taken through the interviews and they were recorded to allow further capturing of information.

3.11 Scientific rigor

3.11.1 Quantitative part (questionnaire)

3.11.1.1 Validity

The questionnaire was evaluated by experts to assess its relevance, and their comments were taken into consideration annex (11) shows the list of arbitrators. Also, a pilot study was conducted before the actual data collection to examine the caregiver's responses to the questionnaire and how they understood it. This had enhanced the validity of the questionnaire after modifying it to be better understood.

3.11.1.2 Reliability

The following steps were done to assure instruments reliability

- Training of data collectors on the caregiver interviewing steps and the way of asking questions. This had assured the standardization of questionnaire filling.
- Then, the data entered on the same day of data collection allowed possible interventions to check the data quality or to re-fill the questionnaire when required.
- Re-entry of 5% of the data after finishing data entry had assured correct entry procedures and decreased entry errors.
- Reliability was measured by Cronbach Alpha and results reflect high reliability. As shown in Table (3.2)

Table (3.2): Reliability estimates for domains and the entire scale

Domain	**Cronbach's Alpha**
QoL Domains	
Physical domain (8 questions)	0.742
Psychological domain (6 questions)	0.760
Social relationships domain (3 questions)	0.607
Environment domain (8 questions)	0.748
Total scale reliability	0.904
PSI Domains	
Parental Distress domain (11 questions)	0.898
Parent-Child Dysfunctional Interaction domain (9 questions)	0.795
Difficult Child domain (8 questions)	0.851
Total scale reliability	0.933

3.11.2 Qualitative part (in-depth interviews)

The following was done to assure the trustworthiness of the qualitative part of this study. First, a peer check was done through experts to revise the in-depth interview questions to assure that they cover all the required dimensions. Then, a member check was done to assure the accuracy and transparency of the transcripts during the interviews. The prolonged engagement was done as the researcher tried to probe for answers and cover all the interview dimensions properly. In addition, recorded interviews and FGD had enhanced tracking up facts and re-check the accuracy of the transcripts. Finally, all the transcripts and recordings were kept for tracking the information by others at any time (Audit trail).

3.11.3 Response rate

All sample members were called on the telephone first then set an appointment for voluntary participation based on informed consent from each one of them before the administration of any tool. The response rate was 99% (396 responded out of 400) and they were replaced. Also, all interviewees who were invited to participate in the FGD had positively responded.

3.12 Data entry and analysis

3.12.1 Quantitative part

Throughout the data collection process, the researcher had reviewed the filled questionnaires on a continuous basis. Before data entry, the researcher had reviewed all questionnaires one by one and corrections were made appropriately. Data entry model was designed and questionnaires and variables were coded and entered into the developed database using the computer software program SPSS. Open-ended questions were entered and coded using the Excel software. The process of data entry was performed in one week from the fieldwork and lasted for an additional two months after the end of the fieldwork. Also, the reentry test was performed on about 5% of the entered data. Then, data cleaning was performed by checking the frequencies of all variables and looking for illogical values. General frequencies were done to figure the responses and to identify missing data for each question. Data re-coding and computation were performed where negatively phrased questions were converted when means are calculated. Thus, the overall scaling went in a logical direction; higher values indicate positive situations (e.g. presence of favorable items or absence of unfavorable items). In addition, central tendency measures were performed including descriptive frequencies, mean, median, mode, standard deviation (SD) and frequency tables. The researcher had used inferential analysis to test the statistical significance of differences. An independent t-test was used to compare the wellbeing and PSI mean scores of the independent variable with two categories such as gender. One-way Analysis of Variance (ANOVA) test was used to compare the wellbeing and PSI mean scores of the independent variables. Additionally, a correlation test was applied to associate the overall wellbeing score and PSI with independent continuous variables such as age. Additionally, a correlation test was applied to associate the overall wellbeing score and PSI with independent continuous variables such as age. Moreover, and the overall PSI with the same variables.

3.12.2 Qualitative part

Open coding thematic analysis technique was used to analyze the transcripts of the in-depth interviews and FGDs. The researcher had obtained the main findings from the transcripts of the interviews and FGD. Then, the categorization of related ideas and comparison and integration between the quantitative and the qualitative findings were done to create rich items for discussion and representation.

3.13 Limitations of the study

- The study is cross-sectional, it reflects the situation in certain moments, which might bias results (Recency bias).
- The interviewed questionnaire was time-consuming.
- Possible recall bias.
- It is possible that some CWDs especially younger ones are not registered and therefore. missed. Those not registered may be the least served ones.
- Limited resources including funds and facilities for data collection and data entry.

Chapter Four

Results and discussion

This chapter presents the results which were consolidated from the responses of interviewed participates and verified through seven FGDs with purposefully selected participants and eleven KII. Statistical analysis of the data and the interpretation of these results will be presented for both quantitative and qualitative data. The descriptive analysis represents an overview of demographic characteristics of respondents, child-related characteristics, WHO wellbeing of respondents and their PSI scores added to the burden of disability on respondents' lives. As the reader moves on, more analytical results show up to figure out key variances and correlations between their characteristics and to explore the statistical significance of differences among groups and categories.

4.1 Descriptive statistics

4.1.1 Demographic characteristics of respondents

The study sample consisted of 400 caregivers with a mean age of 35.5 and SD of 7.7, of the 93% were mothers while 4.8 % were fathers and 2.2% another person. Females were the majority represented by 95%. Caregivers were distributed across the GS by 29% for the Gaza governorate, 23.5% for the North, 20% for Khanyounis,14.8% for the middle and 11.8% for Rafah.

As Table 4.1 indicates 96.5 % of caregivers were married at the time of data collection while 3.5% were never married or widowed. Refugees represented 66.3% of the study; slightly vary from PCBS reported figure of 66.1% (PCBS, 2018). The nuclear family represented 79.7% of the study sample while the rest was represented by extended families. The mean number of children under 18 was 4.2 with 1.87 SD while the mean number of HH members is 7.87 with SD 3.24. Table 4.1 also shows that more than 30% of the HHs have another member in the HH with a disability with HHs having CWD mean number of 0.56 and adults of 0.13 other than the CWD included in the study. In regard to level of education, more than two-thirds of parents were less educated as they attained secondary school degree or less, 23.75% of caregivers attained diploma or university or postgraduate education whereas a higher figure for fathers than the caregivers of 26.07% attained diploma or higher education, these percentages are higher than PCBS figures which of both males and females who attained diploma or higher is 14.4% (PCBS, 2018).

Table (4.1): Distribution of caregivers' responses by demographic characteristics

Variable	N	%
Age		
20-30	131	32.75
31-40	171	42.75
41or more	98	24.5
Total	400	100.0
	Mean: 35.54	Median:35.0
Caregiver		
Mother	372	93.0
Father	19	4.8
Brother/Sister/Other	9	2.2
Total	400	100.0
Gender of caregiver		
Female	380	95.0
Male	20	5.0
Total	400	100.0
Governorate		
North	94	23.5
Gaza	117	29.25
Middle	59	14.75
Khan Yonis	83	20.75
Rafah	47	11.75
Total	400	100.0
Current marital status		
Currently married	386	96.5
Never married/ Widowed	14	3.5
Total	400	100.0
Refugee status		
Refugee	265	66.25
Non-Refugee	135	33.75
Total	400	100.0
Type of family		
Alone/ Nuclear family	319	79.75
Extended family	81	20.25
Total	400	100.0
Number of children under 18 years		
1-3	155	38.75
4-6	229	57.25
More than 6	16	4
Total	400	100.0
	Mean: 4.21	Median: 4.0
Number of HH members in groups		
3-6	149	37.25
7-10	191	47.75
More than 10	60	15.0
Total	400	100.0
	Mean: 7.87	Median: 7.0
Having other HH members with disabilities		
Yes	122	30.5
No	278	69.5
Total	400	100.0
	Mean: 0.70	Median: 1.00

Variable	N	%
Mean number of CWD: 0.56		
Mean number of adults with disability : 0.13		
Caregiver 's educational level attained		
Secondary or less	305	76.25
Diploma or more	95	23.75
Total	400	100.0
Mother's employment status		
Not working	378	94.7
Working	21	5.3
Total	399	100.0
Father's educational level attained		
Secondary or less	292	73.93
Diploma or more	103	26.07
Total	395	100.0
Father's employment status(current)		
Working	238	60.3
Not working	157	39.7
Total	395	100.0
Average HH monthly income from all sources in NIS (for those who answered this question)		
Less than 800	162	61.6
801-1500	81	30.8
More than 1500	20	7.60
Total	263	100.0
	Mean: 837.91	Median: 700.0
The main source of income for the caregiver HH is		
Assistance from UNRWA	156	39.0
Assistance from MOSD	154	38.5
Other sources	90	22.5
Total	400	100.0
Average monthly expenditure		
Less than 800	68	18.5
801-1500	112	30.5
More than 1500	187	51.0
Total	367	100.0
	Mean: 1268.77	Median:1200.0
% of expenditures spent on the needs related to the CWD from the overall expenses		
Less or equal than 40%	127	32.73
41-80%	146	37.63
More than 80%	115	29.64
Total	388	100.0
	Mean:36.48	Median:30.0

The majority of the mothers (94.7%) were not working and that is much higher than the national percent (40.1%) in contrast to father's employment status which was 60.3% and 39.7% were unemployed that is higher than the national figure (24.4%) for unemployed males (PCBS, 2018), while in GS the unemployment reached 48.2%.

Around two-third of HHs (61.6%) lived with income lesser than 800 NIS and the rest is higher (Mean = 837.9 and Median=700). The main source of income for caregivers HHs was almost equal between assistance from UNRWA and MOSD (39%, 38.5%). In spite of the low average income, the average monthly expenditure is reversed where nearly half of

HHs (51.0%) expend more than 1500 NIS, 30.5% expend between 801 and 1500 (Mean=1268.77, Median=1200). Going with average expenditure, 32.7% of respondents expended more 40% or less from their expenditure on CWDs needs while 37.6% spent between 41-80% and around the third spent more than 80% on CWDs needs of their total expenses. Economic situation figures in this study are consistent with figures according to a study that studied demographic changes for Palestine 2030 which indicated that 67.1% of the Gazan population is below the poverty line (Courbage, Abu-Hamad & Zagha, 2016).

4.1.2 Child individual characteristics

Highlighting the CWD characteristics, the male children were more than females with 51.7% representation and 48.3% for females, this goes with PCBS statistics where males were 58.9% and females were 41.1% (PCBS, 2012) and according to the 2017 Census of Population, Housing and Establishments, at least 0.9% of children are disabled (0.7% in the West Bank and 1.2% in the GS), 1.1% of boys and 0.8% of girls (PCBS, 2018). While the mean age was 8.14 and median of 8, most of the CWDs did not exceed the primary education stage with 38.44% and only 10.1 % attained preparatory stage or above adding to 27.04% were not in education at all. More than half of the educated children attained standard education (53.5%) and the rest were in special education. In comparison with the study of Jones et al. (2016) where the CWDs who were enrolled at that time in Gaza constituted 44.5% (Jones et al., 2016), which is apparently higher from the study results, however, the difference is may be attributed to the way the question was asked. In this study, the higher level of education was asked but, in Jones et al., the study asked if the CWD is currently enrolled in education.

The nature of disability of the child was classified to be represented by its category with adequate number, 19.25% was the representation of the physical/ mobility disability, followed by the multiple disabilities of 19%, then by learning and cognitive with 17.75%, 16.0% for hearing and speech disability, 15% for visual disability and 13% for the behavioral disability. The percentages of PCBS reported that communication disability was the most prevalent by 25.25%, followed by physical or mobility by 25.1% then remembering and focus by 19.7% and the least was hearing by 13.2% (PCBS, 2018).

Table (4.2): Distribution of CWDs according to demographic characteristics

Variable	N	%
Sex of CWD		
Male	207	51.7
Female	193	48.3
Total	400	100.0
Age of CWD		
1-4	94	23.5
4.1-6	56	14.0
6.1-10	119	29.75
10.1-18	131	32.75
Total	400	100.0
	Mean: 8.1475	Median:8.00
The highest level of education attained by CWD		
Kinder garden	75	24.42
Primary	118	38.44
Preparatory and above	31	10.1
Not in education	83	27.04
Total	307	100
Type of the education for those in education		
Standard education	122	53.5
Special education	106	46.5
Total	228	100.0
The nature of disability		
Visual/seeing	60	15.0
Physical/mobility	77	19.25
Behavioral	52	13.0
Hearing/speech	64	16.0
Learning and cognitive	71	17.75
Multiple Disabilities	76	19.0
Total	400	100.0
The age the child acquired disability: At birth		
No	95	23.75
Yes	305	76.25
Total	400	100.0
The years the child has the disability		
0-3	88	22.0
3.1-6	91	22.8
6.1-10	113	28.2
10.1-18	108	27.0
Total	400	100.0
	Mean: 7.3675	Median:7.00

This difference was due to the stratification of the sample where taking enough numbers of each type of disability was a priority than its representation in percentage. As Table 4.2 indicates that 76.25% of the children acquired their disability at birth and the longest time the child had the disability in terms of years was 28.2% for 6.1-10 years with average mean 7.36.

4.1.3 Quality of life domains

The study instrument for QoL consisted of 26 scale-questions. They represent 4 domains; physical aspects, psychological aspects, social relationships, and environment. A Likert scale that starts from 1 indicating the least value (Strongly disagree/Not at all) and 5 indicating the highest one (Strongly agree/Extremely) was used in the instrument. Responses of caregivers were calculated by computing them then, dividing them by the number of questions that build the whole domain. The overall rating of each domain was indicated by the mean percent as detailed below in Table 4.3.

4.1.3.1 Overall wellbeing status of GS population

As listed in Table 4.3, the overall wellbeing of the study respondents elicited a moderate average (mean = 2.9; mean % =58%). The following section describes the scoring of individual questions, the overall rating of each domain and the total scale scoring.

Table (4.3): Summary of wellbeing domain scores and overall QoL

Domain	No. of items	Mean	Median	Standard deviation	% Mean
Physical Health	7	3.2243	3.2857	0.63131	64.48
Psychological	6	3.0308	3.1667	0.69691	60.61
Social relationships	3	3.4008	3.6667	0.84608	68.01
Environmental	8	2.6334	2.6250	0.68623	52.66
Overall	25	2.9997	3.0385	0.59530	58

The converted data had been calculated to indicate every domain and the mean. Obviously, the mean percent of most of the domains converged around 60% while one domain was lesser than 60% as shown in figure 4.1. The environment domain elicited the least score (mean = 2.63) as detailed in the coming sections. At the same time, the general question about overall wellbeing was reported to be good or very good combined only by a quarter as shown in Figure 4.2.

In contrast to Al-Bayoumi's study results (2014) where results of the mean percent wellbeing domains were converged around 75% and similar to this study environmental domain elicited the least mean (mean= 3.25) and the highest was the physical health domain (mean=3.79).

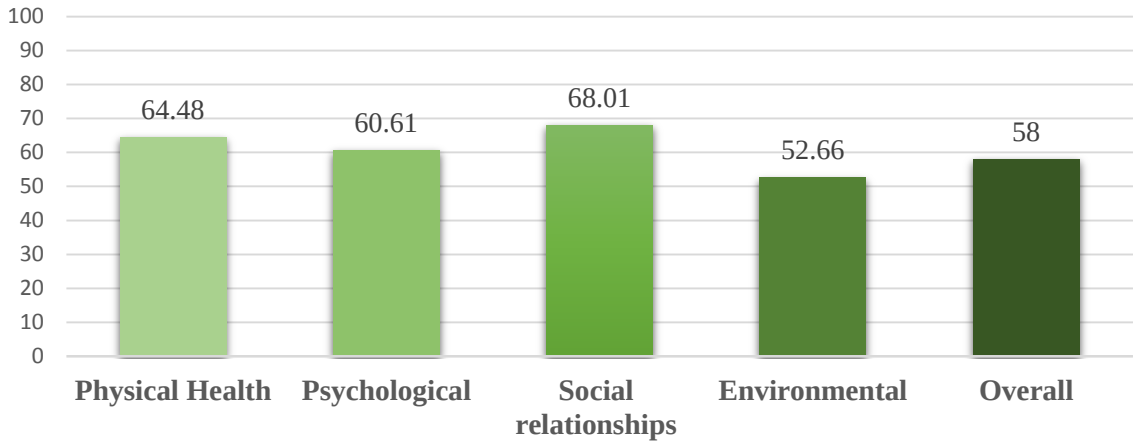

Figure (4.1): Wellbeing domain scores

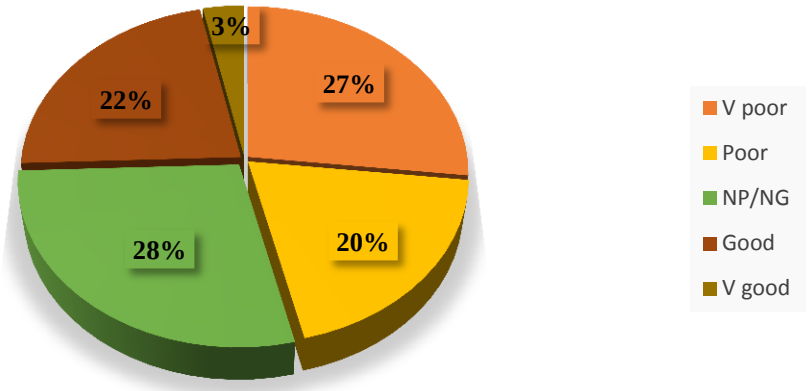

Figure (4.2): General wellbeing satisfaction of caregivers

The results of this study go with the Jordanian QoL scores which indicated that the overall QoL score was 60% (Awamleh, 2015). A father of two children of hearing disability reported about his QoL, *"Any father or mother who has a CWDs is very tired and faces many things that make him sad, he may be satisfied from a religious point of view but indeed there were moments I wished to die."*

Countries like OECD countries have variations in the subjective QoL, they fall into three groups; The first group of countries has a relatively low level of average LS compared to other countries, with average scores of less than 5.5 out of 11(less than 50%). This group includes some OECD countries (Hungary, Portugal, Estonia, and Turkey) and some emerging economies (China, South Africa, and Indonesia). The second group of countries comprises much of the OECD and Brazil and records average LS scores below 7(63.6%). Finally, the highest achieving group comprises only OECD member countries,

predominantly Nordic European and some Anglophone countries. Average LS scores for this latter group is above 7(63.6%).

Key informants were asked about how they notice the general QoL of the families they serve, he pointed that, *"The parents who have a CWD are always in need, even if the father is a minister, the requirements are extreme."*

4.1.3.2 Physical health domain

The study participants reported a moderate level of satisfaction about their health with a mean of 3.41 (68.2%) which is slightly higher than the overall physical health domain which was 64.48%. In a study of QoL for parents with children who have autism in Erbil Iraq, mothers reported a low mean of physical domain 41.55% compared to the study respondents. Comparing the study results with a very near country which is Jordan where the level of QoL among Jordanian families of CWDs was searched, it reveals that 56.3% was the mean QoL of the physical health domain which is slightly lower than the reported results (Awalmeh, 2015). It is noteworthy that a partial explanation of higher physical domain scores in the study is attributed to the age of the study sample where more than two-third of the respondents are below forty. In this study, 18% of people suffered from pain that prevents doing activities and ranged from very much to an extreme amount. Compared to American caregivers 26% said their health was fair or poor and One-quarter of caregivers of children feel caregiving has made their health worse (24%) (National Alliance of caregiving, 2009). A sister of a girl who has spastic CP and developed scoliosis problem in her back said, *"My sister can't walk and she is big and heavy, my mom carries her and I help her and sometimes my siblings, mom had discs in her back because of carrying her and I have a curve in my back. we can't leave her alone, now we created a system of shifts where always someone should watch her out."*

Obviously, as findings in Table 4.4 indicate, respondents reported the need for medication to function in daily life, as 24.25% needed medications very much and in an extreme amount. Only 10% reported having a good ability to get around. As noticed from the findings, around two-third of study respondents were moderate to very much having enough energy for everyday life and were satisfied with their ability to perform ADL. Table 4.4 also indicates that 32.25% of the respondents were dissatisfied with their sleep and 45.5% were satisfied (satisfied and very satisfied combined).

Table (4.4): Distribution of responses of caregivers by the physical domain of wellbeing

Item		V dissatisfied	Dissatisfied	NS/ND	Satisfied	V satisfied	Mean
Satisfaction with health	No	37	65	49	195	54	3.41
	%	9.25	16.25	12.25	48.75	13.5	
		An extreme amount	**V much**	**A moderate amount**	**A little**	**Not at all**	**Mean**
Extent of physical pain that prevents from doing what needed to be done	No	11	62	142	104	81	3.46
	%	2.75	15.5	35.5	26.0	20.25	
Medical treatment needed to function in daily life	No	10	87	94	66	143	3.61
	%	2.5	21.75	23.5	16.5	35.75	
		V poor	**Poor**	**Neither poor nor good**	**Good**	**V good**	**Mean**
Ability to get around	No	99	144	117	40	0	2.25
	%	24.75	36.0	29.25	10.0	0	
		Not at all	**A little**	**Moderate amount**	**V much**	**Extreme amount**	**Mean**
Enough energy for everyday life	No	33	55	136	150	26	3.20
	%	8.25	13.75	34.0	37.5	6.5	
		V dissatisfied	**Dissatisfied**	**NS/ND**	**Satisfied**	**V satisfied**	**Mean**
Satisfaction of sleep	No	56	73	89	162	20	3.04
	%	14.0	18.25	22.25	40.5	5.0	
Satisfaction with the ability to perform daily living activities	No	17	49	75	229	30	3.52
	%	4.25	12.25	18.75	57.25	7.5	
Satisfaction with capacity for work	No	18	50	80	219	33	3.50
	%	4.5	12.5	20.0	54.75	8.25	
Overall physical health mean:		3.22 out of 5				64.48%	

A mother of autistic child said about sleep, *"I miss to feel that I am full of sleep, I do not sleep because my son may wake up at two or three o'clock and start moving around, he can open the door and go out, he can go to the kitchen and break plates or use a knife, he always wants to eat, many times I found him opening the refrigerator and dropping food on the floor, I prepare the house before sleeping, I close everything he can reach, hide any taps or laptop, I adapt the home for sleeping every night because I am afraid to fall asleep and not notice him if he wakes up."*

Going with the previous figure's respondents reported high satisfaction with their capacity for work of 63.1%; (satisfied and very satisfied combined). Chambers & Chambers (2015) reported in their study on effects of caregiving on the families of CWDs and adults with disabilities that 70% of mothers of CWD have low back pain, has higher incidence of migraine headaches, gastrointestinal ulcers, increased overall stress, and even has 40% chance of having sleep disorders and depression (Cambers & Chambers, 2015).

4.1.3.3 Psychological domain

This domain focuses on the extent and frequency of experienced positive and negative feelings, the acceptance of body appearance and satisfaction of self.

Table (4.5): Distribution of responses of caregivers by the psychological domain of wellbeing

Item		**Not at all**	**A little**	**Moderate amount**	**V much**	**Extreme amount**	**Mean**
Life enjoyment	No	67	112	169	44	8	2.54
	%	16.75	28.0	42.25	11.0	2.0	
Feeling life to be meaningful	No	36	90	178	82	14	2.87
	%	9.0	22.5	44.5	20.5	3.5	
Ability to concentrate	No	42	55	118	163	22	3.17
	%	10.5	13.75	29.5	40.75	5.5	
Acceptance of bodily appearance	No	21	44	59	197	79	3.67
	%	5.25	11.0	14.75	49.25	19.75	
		V dissatisfied	**Dissatisfied**	**NS/ND**	**Satisfied**	**V satisfied**	**Mean**
Satisfaction with yourself	No	24	40	51	201	84	3.70
	%	6.0	10.0	12.75	50.25	21.0	
		Always	**Very often**	**Quite often**	**Seldom**	**Never**	**Mean**
Having negative feelings such as blue mood, despair, anxiety, depression	No	88	198	66	28	20	2.24
	%	22.0	49.5	16.5	7.0	5.0	
Overall psychological domain mean:		3.03 out of 5				60.61%	

The average score of the psychological domain was 60.61% with a mean of 3.03 out of 5 which was consistent with the previously mentioned study from Jordan which evaluated the level of QoL among Jordanian families of CWDs with psychological score of 61.1% (Awalmeh, 2015). The aspect of life enjoyment was reported to be lower than the other aspects in this domain (more than 44%; a little and not at all) like the feeling of meaningfulness of life, ability to concentrate, but the lowest mean was about the frequency

of having negative feelings. The percentage of respondents reported very much and an extreme amount of the ability to concentrate was 46%. A mother of four children with visual disabilities and a wife of a person with physical disability reported, *"My life is different than others, me and my children don't go outside after sunset because they do not see at night, we have a different lifestyle but we suffer a lot from the surroundings even my family they call my children with names like the kid with four eyes because of the glasses, I feel deeply hurt when I hear such talks."*

Nearly two-thirds of the respondents showed a high acceptance of bodily appearance. General satisfaction with self was the highest mean average in this domain with a 3.7 mean score and more than 70% of respondents were satisfied with themselves which may be attributed to the religious and spiritual factor in Gaza's culture. In contrast, the percentage of having negative feelings is reversed where more than 70% of the respondents suffer from negative feelings which is reasonable because of the difficulties faced due to caregiving process, these findings are consistent with results of a study searched the mental health, social distress, and political oppression: in the occupied Palestinian territory (Giacaman et al., 2004) which found that almost one in two Palestinians live with distress, anxiety, worry, and grief. In addition, more than one in three Palestinians feel deprived and more than one in three Palestinians feel that suffering is part of their life while more than one in three Palestinians are fed up with life (Giacaman et al., 2004). One mother of two CP children and one of them had died explained about the extremely negative feelings, *"I was with my daughter in the hospital for a year and two months, I did not go out one day which affected my psyche, even I spent Ramadan and holidays at the/al Shifa hospital, I was depressed, I thought to have a drug to suicide".*

4.1.3.4 Social relationship domain

This domain focuses on the support provided and received from the people around them. Surprisingly the mean elicited score of this domain was 3.40 (68.01%) which was the highest among domains, maybe because the number of questions is low and many reported satisfaction about sex. It is lower than the findings of Al-Bayoumi (2014) in Gaza where the overall score was 75.9% in adults generally. Table 4.6 indicates that more than 60% of respondents reported good and very good satisfaction with their relationships while in Al-Bayoumi study (2014), 85% reported being good and very good.

Table (4.6): Distribution of responses of caregivers by the social relationships domain of wellbeing

Item		V dissatisfied	Dissatisfied	NS/ND	Satisfied	V satisfied	Mean
Satisfaction with personal relationships	No	17	61	70	169	83	3.60
	%	4.25	15.25	17.5	42.25	20.75	
Satisfaction with sex life	No	17	34	99	195	55	3.59
	%	4.25	8.5	24.75	48.75	13.75	
Satisfaction with the support got from friends	No	65	82	92	106	55	3.01
	%	16.25	20.5	23.0	26.5	13.75	
Overall social relationship domain mean:		3.40 out 5				68.01%	

A mother of a physical and autistic boy and her husband is person with disability reported, *"I brought my child after ten years and he had many health problems and he fell from the fourth floor, he needed many surgeries, when he became older I started to take him from place to place and from association to another, the family was blaming me and calling me crazy to do that for a hopeless child and pay a lot of money, since then my life has changed, they used to call "freshwoman" but now I do not socialize, even when my mother had a stroke my sisters didn't give me a shift to watch her out because they know that my child is very bothering and I don't bear any comments."* Similarly, for satisfaction with sex life, respondents showed more than 60% good and very good satisfaction. However, a lesser percentage (40.3%) of satisfaction with friends support and more than the third were dissatisfied. A mother of a child with visual disability reported about the support from her family, *"My problem is with my family, my brother call my son and ask him" how many fingers are those?" they call my son with names,; the blind; the squint, the boy with four eyes, he hated his glasses because of them and preferred not to see on hearing those words."* As mentioned before in literature, the social support for mothers of children with mental retardation and mothers of healthy children was with statistically significant differences (Kerenhappachu & Sridevi, 2014). In some Arab countries like Iraq, QoL for parents with children who have autism was studied where the social domain scored 53.62% which is lower than this study (Kareem & Ali, 2014). Sometimes the differences among different scores may be attributed to the cultural and social context but at other times, it may be related to the nature of disability because some types of disability need more time and effort than the others which do not allow space for social relationships.

4.1.3.5 Environment domain

The environment domain focuses on feeling safe and secure. It also considers the comfort in the place of residence, worries about financial difficulties, and access to opportunity for leisure.

Table (4.7): Distribution of responses by the environmental domain of QoL

Item		Not at all	A little	Moderate amount	V much	Extreme amount	Mean
Feeling safe in daily life	No	70	115	134	69	12	2.60
	%	17.5	28.75	33.5	17.25	3.0	
Healthy physical environment	No	62	100	102	111	25	2.84
	%	15.5	25.0	25.5	27.75	6.25	
Having enough money to meet needs	No	63	84	101	130	22	2.91
	%	15.75	21.0	25.25	32.5	5.5	
Availability of the needed information in day-to-day life	No	31	64	158	139	8	3.07
	%	7.75	16.0	39.5	34.75	2.0	
Opportunity for leisure activities	No	86	132	98	77	7	2.47
	%	21.5	33.0	24.5	19.25	1.75	
		V dissatisfied	**Dissatisfied**	**NS/ND**	**Satisfied**	**V satisfied**	**Mean**
Satisfaction with the conditions of living place	No	98	61	49	143	49	2.96
	%	24.5	15.25	12.25	35.75	12.25	
Satisfaction with access to health services	No	136	126	63	69	6	2.21
	%	34.0	31.5	15.75	17.25	1.5	
Satisfaction with transport	No	177	97	74	48	4	2.01
	%	44.25	24.25	18.5	12.0	1.0	
Overall environmental domain mean		2.63 out of 5				52.6%	

This domain elicited 2.63 mean score out of 5 (52.6%) as illustrated in Table 4.7 which is the least mean among all domains and it is lower than the stated average of (WHO, 2004) which was 13.5 or 67.5%, this may be explained by the difficult economic and unstable political context in Gaza. Only 20.3% of respondents were feeling safe in daily life (very much and extreme). Similarly, nearly a third of respondents only was having a healthy environment. In spite of high poverty rates in Gaza, 38% of respondents reported having enough money to meet their needs. This percentage may be explained by cultural beliefs of

being satisfied with their livelihood. A brother of three boys and a girl with CP reported, *"My siblings don't speak, don't move, they only crawl and make sounds, when my father wants to bath them, it's very difficult because we had one wheelchair and it is ruined, I stay with them but they are noisy, and Karam want "Toyor al Janna" all the time. My father buys nappies for them because the association stopped giving us their nappies, some people from associations come to our home just to take photos and go."* This result is supported by Kareem & Ali's study (2014) which was in Iraq that scored the environmental domain the least with an average mean of 34.73%.

With regard to the availability of information needed, more than the third were having the needed information. Dissatisfaction about the access to opportunity for leisure activities was high with 54.5% percentage and only 21.1% were satisfied. Nearly 40% of respondents were dissatisfied with the conditions of living place while the half were satisfied. Table 4.7 shows that high dissatisfaction with access to health services (65.5%) and transport (68.6%) was reported and lesser than 20% of satisfaction for both aspects. A key informant who is a member in advocacy groups for disability reported, *"The families and CWDs who receive any service are face difficulties, the first is transportation, they can't afford transportation cost, another lack of information needed, they don't know from where to seek services and they rotate around associations and ask for services and they finally don't take them, even MOSD does not have the whole information, there is no network to join them, also they lack home adaptation."*

4.1.4 Parental stress index

This tool is a self-report screening tool that helps caregivers and families identify the sources and different types of stress that come with parenting. It has three components; Parental Distress (PD) which identifies the extent to which parents feel competent, restricted, conflicted, supported, and/or depressed in their role as a parent or caregiver, Parent-Child Dysfunctional Interaction (P-CDI) which identifies the extent to which parents feel satisfied with their child and their interactions with them and Difficult Child (DC) which identifies how a parent perceives their child to be, whether the child is easy or difficult to take care of in addition to total stress which gives indication of overall level of stress a caregiver is feeling in their role as a parent.

Table (4.8): Summary of PSI domains and overall parental stress

Domain	No. of items	Mean	Median	Standard deviation	% Mean
Parental Distress (PD)	11	2.62	2.5	0.744	52.4
Parent-Child Dysfunctional Interaction (P-CDI)	9	2.8513	2.7778	0.67184	57
Difficult Child (DC)	8	2.8566	2.7500	.82333	57
Overall stress score	28	2.7646	2.6429	.65822	55.2

A Likert scale that starts from 1 indicating the least value (Strongly agree) and 5 indicating the highest one (Strongly disagree) was used in the instrument so a higher score means less stress. Responses of caregivers were calculated by computing them then, dividing them by the number of questions that build the whole domain. The overall rating of each domain was indicated by the mean percent as detailed below in Tables 4.8 and shown in Figure 4.3.

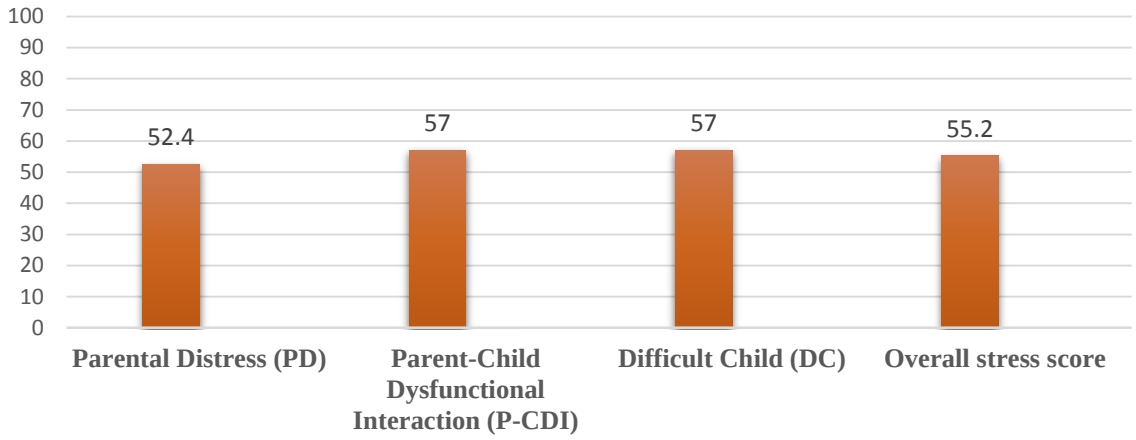

Figure (4.3): Parental stress domains and overall stress domains

As listed in Table 4.8 the overall stress score of the study respondents elicited an average of is 2.7 out of 5 (54%). The mean percent of all domains converged around 50% total stress. In a previously mentioned study in literature where it was conducted in Malaysia to investigate PSI in parents of enuretic children, the total stress mean was 93.41 that equals 51.8% (Roccella et al., 2019) which is close to the results of this study. In the study of Lima, Cardoso & Silva (2016) the mean PS total score was 88.4; 42% of the participants were classified as having clinical stress on the global scale, given that their scores were 91 or higher, i.e., corresponding to the 90th percentile or over.

On another side in Jordan, a study was conducted on Jordanian parents of children with autistic disorder. which resulted in that those parents experienced significant high levels of parental stress that approximately 89% of the parents reported stress scores higher than 90 (Dardas, 2014).

4.1.4.1 Parental distress (PD)

The study respondents reported a moderate level of PD with an average mean of 2.5 (50%) while in Roccella et al. (2016) the mean was 22.36 which equals 37.2%. The results of this study are much higher than Roccella et al. (2019) study which indicated that there were variables that might affect the stress like the individual characteristics of parents or the child nature of disability also going with the results of Roccella et al. (2019), Lima, Cardoso & Silva (2016) had resulted that PD had the second-highest proportion of participants classified as having clinical stress (33%). Dardas (2014) study of Jordanian parents revealed that PD was (40.29 out of 60;67.15%) which is much higher than the study score, however, both scores are considered high which may be attributed to the culture of Arabs; it is an extremely important responsibility to bring children up so that they will be reflected well on the family. Arabs have the tendency to rely on the responsibility of their child's successes on parents and much of the blame for their failures.

Most of the respondents felt that cannot handle things very well with nearly 60 % for those who agreed and strongly agreed compared to (Dardas &Ahmad, 2014) study where the mean was 3.5;70.6% which is higher in Jordan. Obviously, most caregivers (83.5%) found themselves self-giving up of life than ever expected while only 11% did not alike Jordanian parents who were 82% (Dardas & Ahmad, 2014).

Confirming this point a mother of child with visual disability reported, *"I was divorced when my son was two months pregnant, I am fully responsible of my child and his father has no relation with him, he is my life, I am thirty-one now, I feel that I am giving up the chance to continue my life for him."* Similarly, a high percentage of caregivers felt trapped by responsibilities as a caregiver (71.3%) but Jordanians were a little higher of 73% (Dardas & Ahmad, 2014).

Table (4.9): Distribution of responses by parental distress domain of PSI

Item	SD		D		N		A		SG	
	No	**%**	**No**	**%**	**No**	**%**	**No**	**%**	**No**	**%**
The feeling that cannot handle things very well	14	3.5	53	13.25	95	23.75	216	54.0	22	5.5
Finding self-giving up more of life to meet the child's needs than ever expected	15	3.8	29	7.2	22	5.5	194	48.5	140	35.0
Feeling trapped by responsibilities as a caregiver	17	4.25	47	11.75	51	12.75	191	47.75	94	23.5
Since having the child have been unable to try new and different things	24	6.0	81	20.25	94	23.5	165	41.25	36	9.0
Since having the child, the feeling that almost never able to do things that like to do	25	6.25	75	18.75	91	22.75	174	43.5	35	8.75
Unhappiness with the last purchase of clothing made for self	20	5.0	90	22.5	105	26.25	134	33.5	51	12.75
A few things that bother about life	10	2.5	34	8.5	35	8.75	248	62.0	73	18.25
Having a child has caused more problems than expected in relationship with spouse/family.	82	20.5	183	45.75	37	9.3	77	19.25	21	5.25
Feeling alone and without friends when going to a party, usually expect not to enjoy	38	9.5	118	29.5	81	20.25	132	33.0	31	7.75
Not interested in people as used to be	21	5.25	92	23.0	64	16.0	188	47.0	35	8.75
Not enjoying things as used to	18	4.5	72	18.0	56	14.0	207	51.75	47	11.75
Overall PD mean	2.62 out of 5				52.4%					

Of the respondents, 50.3% said that since having the child they were unable to try new and different things but the percentage in (Dardas & Ahmad, 2014) study was 66.8% of respondents. There were quite a few things that bother more than 80% of the respondents in their lives. It is clear from data in Table 4.9 is that 66.3% of respondents had no problems with their spouse or family because of having the child, unlike Jordanians who 48% of them had no problems with spouse or families (Dardas & Ahmad, 2014). A father stated about what disability of his child affected his relationship with his wife, *"I was late for 5 years until I brought my child and I was satisfied and thankful to god, the child appeared to be sick and became CP, at the same time my wife had problems in pregnancy and I made for my wife laboratory analysis and the results revealed that its 40% could be congenital problem, so now I got engaged to bring support to my son in the future."*

More than one-third of caregivers felt alone and without friends when going to a party and expected not to enjoy while, more than half were not interested in people as they used to be. This percentage is consistent with the percentage of respondents who are no more enjoying things which is 63.5%. All three later questions supported by Dardas & Ahmad study (2014) which ranged from 60%-70%.

4.1.4.2 Parent-Child dysfunctional interaction (P-CDI)

This domain focuses on the interaction between child and parents and how it is perceived by the caregiver. The average elicited score of the P-CDI domain was 57%. Comparing to Roccella et.al (2019) that resulted a mean score in this domain of 40.4% (24.29), the P-CDI of the study is higher where the nature of the child disability may attribute to this difference specifically that Roccella et al. (2019) study was conducted on parents of enuretic children while this study included all types of disabilities. Moreover, Lima, Cardoso & Silva (2016) resulted in P-CDI domain was the main source of stress; 45% of the participants were classified as having clinical stress. On the other side in Jordan Dardas &Ahmad study (2014) the score was 62.8% and was conducted on parents of autistic children. As shown in Table 4.10, 59.3% of caregivers reported that their child rarely did things that made them feel good at the time that only comparing to Dardas & Ahmad study (2014) where the percent was 67.2% of who agreed. Nearly one-third of the children were less smiling than expected while half of them were not while in autistic children in Jordan 70.5% were not (Dardas & Ahmad, 2014). The percentage of respondents who felt that their efforts were not appreciated very much was almost equal to the percentage of respondents who felt the opposite which was around 40% but was higher in Jordanian parents of 52.3% (Dardas & Ahmad, 2014).

As for the child playing, it seems that a high portion of children was giggling or laughing when they were playing with a percentage of respondents who agreed with that of 70.8% in contrast with autistic children where less than the half were giggling or laughing during playing (Dardas & Ahmad, 2014).

Table (4.10): Distribution of responses of caregivers by P-CDI domain of PSI

Item	SD		D		N		A		SG	
	No	**%**	**No**	**%**	**No**	**%**	**No**	**%**	**No**	**%**
The child rarely does things feels good	22	5.5	74	18.5	65	16.25	206	51.5	33	8.25
Feeling that the child likes and wants to be close to the caregiver	13	3.25	27	6.75	19	4.75	212	53.0	129	32.25
The child smiles much less than expected	55	13.75	146	36.5	58	14.5	118	29.5	23	5.75
When doing things for the child, getting the feeling that efforts are not appreciated very much	32	8.0	128	32.0	77	19.25	140	35.0	23	5.75
When playing, the child doesn't often giggle or laugh	68	17.0	215	53.75	39	9.75	68	17.0	10	2.5
The child doesn't seem to learn as much as most children	29	7.2	74	18.5	45	11.25	189	47.25	63	15.75
The child is not able to do as much as I expected	28	7.0	58	14.5	46	11.5	208	52.0	60	15.0
Expectation to have closer and warmer feelings for the child	77	19.25	191	47.75	54	13.5	69	17.25	9	2.25
P-CDI mean	2.85 out of 5				57%					

However, the percentage is reversed as for learning as much as most children which was indicating that 63.1% of respondents believed that their children did not learn like the other children and this goes with Dardas & Ahmad (2014), also it is consistent with the percentage of respondents who were believing that their child was not able to do as they expected. Near 20% of respondents expected to have closer and warmer feelings for the child and siblings in contrast to Jordanian parents who reported a higher percent of 60.4%.This point was indicated by a young mother who had her first boy to be CP, *"after I brought my child, my mother in law keeps calling my husbands with names and humiliate him because he can't bring food and other things, he stopped playing with my child because of her humiliation, even me, I feel that I just throw him anywhere and I do not feel like playing with him."*

4.1.4.3 Difficult child (DC)

The last domain in PSI is the DC domain which focuses on the child's behaviors and reactions and how the caregiver perceives them. This domain elicited 2.85 mean score which is similar to the P-CDI domain score similarly to Roccella et al. study (2019) where the mean score of DC domain turned out to be the same of P-CDI score which supported

the results of this study, however, 22% of the participants of Lima, Cardoso & Silva (2016) study were classified as having clinical stress based on the scores corresponding to the DC domain.

Table (4.11): Distribution of responses of caregivers by DC domain of PSI

Item	SD		D		N		A		SG	
	No	%	No	%	No	%	No	%	No	%
The child generally wakes up in a bad mood	48	12.0	123	30.75	86	21.5	111	27.75	32	8.0
feeling that the child is very moody and easily upset	28	7.0	84	21.0	63	15.75	177	44.25	48	12.0
The child does a few things that bother a great deal	27	6.75	80	20.0	55	13.75	174	43.5	64	16.0
The child reacts very strongly when something happens that the child doesn't like	20	5.0	66	16.5	55	13.75	193	48.25	66	16.5
Sleeping and eating schedule was much harder to establish than expected	35	8.75	125	31.25	57	14.25	145	36.25	38	9.5
The child turned out to be more of a problem than expected	35	8.75	129	32.25	59	14.75	143	35.75	34	8.5
The child makes more demands than most children	43	10.75	104	26.0	48	12.0	153	38.25	52	13.0
The child seems to cry more often than most children	66	16.5	147	36.75	58	14.5	101	25.25	28	7.0
DC mean	2.85 out of 5					57%				

As for Jordanian parents, they scored 66.5% which is higher than the study (Dardas & Ahmad, 2014). It appears that more than one-third of the children wake up in bad mood while 56.3% of respondents had the feeling that the child was very moody and easily upset which is the same as Jordanian autistic children (Dardas & Ahmad, 2014). This goes with the percent of respondents who agreed that their child did a few things that bothered a great deal (59.5%) but was higher in Dardas & Ahmad study (2014) with percent of 77.6%. A mother of hyperactive and learning disability child said, *"When my son was younger, I was not feeling that he was problematic, but as he grows his activity increases and he destroys everything he sees if he passes from any place, All my day is just consumed in picking up after him, sometimes I feel like wishing him the worst.* "A high portion of children were reported to be reacting very strongly when something is not liked to happen by 64.8% of respondents while Jordanian children reported being 77.4% reacting strongly (Dardas & Ahmad, 2014).

Schedules of eating and sleeping of children were reported to be harder to establish than expected by 45.8% of respondents but parents of autistic children reported that 60.8% was harder than expected (Dardas & Ahmad, 2014). Similarly, 44.3% of respondents reported

that their child turned out to be more of a problem than expected. Nearly half the caregivers reported that their child made more demands than most of the children but lesser percent was reported on child crying more often than most children of 32.2%. With higher percentages of reporting the autistic children to be more demanding and cried more often, parents reported more than 70% agreement for both questions.

4.1.5 Service provision

This domain sheds the light on services provided and whether they were adequate or not for those who received the services, also whether services were helpful or not for those who received them and if the respondents faced a burden in seeking these services**.** In spite of that less than half of the study, respondents received health services, but it appeared to be the highest service provided to respondents of the study. Among those who received only 25.8% reported that health services were adequate while most of the respondents (90.5%) who received health services reported that the service was helpful and surprisingly 80% faced a burden in seeking the service. A mother of a multiple disability girl explained, "*I tried a lot with associations and asked a lot to provide us the medications, the first response is your husband is an employee even if his income only 50 NIS, he is named employee on the computer, to the extent that the social worker felt sympathy for me and asked me to bring a sign from the manager and a note written as (private), I stopped trying because it is enough embarrassments."* Jones et al. (2016) survey reported that only 19.5% had have health insurance and a very high percentage of families of CWDs pay out of pocket for seeking medical services like special medical care (60%), medication (59.2%).While a key informant reported about health services, *"The health services are provided as any beneficiary and a special service for the CWD , for example if the child in need to a device, MOH provides it either with contribution or not according to his reports, and sometimes as MOH lends the device if it is very expensive, but sometimes this provision is connected to the availability of resources in MOH, and sometimes according to waiting lists, we try our best and if we can't provide the service we refer or guide the parents where to go. Of course, the view is not that beautiful but there are efforts for improving. also, the problem is many services were provided as projects so there is no continuity of the services if existed."*

Table (4.12): Distribution of responses of caregivers by service provision in the study period

Type of service	Received		Adequate		Helpful		Face a burden	
	No	**%**	**No**	**%**	**No**	**%**	**No**	**%**
Health services	170	42.5	44	25.88	154	90.58	136	80.0
Educational services	153	38.3	67	43.79	137	89.54	3	1.96
Financial assistance	48	12.0	2	4.16	45	93.75	43	89.58
Outreach services	105	26.3	38	36.19	92	87.61	55	52.38
Psychosocial services	113	28.2	67	59.26	101	89.38	37	32.74

Type of therapy/medical care has been provided to CWD this year	**N**	**%**
Medications	128	32.0
Medical follow up	128	32.0
Speech/language therapy	114	28.5
Physiotherapy	111	27.8
Occupational therapy	93	23.3
Specialized medical care	83	20.8
Assistive devices	78	19.5
Provision of disposables such as diapers, dressings	73	18.3
Psychosocial/mental health	52	13.0
Audiology services	29	7.2
Orthopedic/prosthetic therapy	13	3.3
If caregiver received training or counseling about how to deal with CWDs		
Yes	268	67.0
No	132	33.0
Total	400	100.0
If caregiver received training or counseling about how to deal with CWDs ever, since acquiring the disability		
Training or counseling on how to deal with CWDs	253	63.2
Counseling on the basic care	249	62.3
Dealing with the health aspect of the care	248	62.0
Dealing with the assistive devices	152	38.0
Dealing with the education aspect	162	40.5
Home-based care	227	56.8
If caregiver received training or counseling about how to deal with CWDs in the past year		
Training or counseling on how to deal with CWDs	177	44.3
Counseling on the basic care	168	42.0
Dealing with the health aspect of the care	169	42.3
Dealing with the assistive devices	102	25.5
Dealing with the education aspect	106	26.5
Home-based care	157	39.3
If the caregiver doesn't receive any service		
No	269	67.25
Yes	131	32.75
Total	400	100.0
If the caregiver needs services that are not provided		
No	90	22.5
Yes	310	77.5
Total	400	100.0

As for educational services, the percentage is noticeably lower than health services where only 38.3% received the service. Of those who received 43.7% found the service to be adequate and the majority (89.5%) found it to be helpful. Moreover, as Jones et al. (2016) reported that CWDs had unmet needs regarding education continuity where 45.5% needed supportive teachers which was not available. The study of Mathye & Eksteen (2016) which was conducted in South Africa supported the findings of this study. As previously mentioned in the literature, caregivers reported challenges with accessing social assistance grants, health-care services, educational and recreational facilities, and other public infrastructure (Mathye & Eksteen, 2016).

The least provided services were the financial services which only 12% of the respondents received, also among who received only 4.1% reported that the service was adequate while nearly 90% faced burden in seeking financial services, these findings are going with the Jones et al. (2016) findings which reported that 71.6% had faced high financial difficulties in relation to expenses of disability and 18.6% faced average difficulties. This may be attributed to the very difficult and complicated economic situation that lived in Gaza. A father of a two physical mobility disability boy and girl reported, "*When I went to MOSD to seek a financial assistance, they refused to help me because I am registered as an employee, while at the same time I know a person who submitted fake documents and they took the financial assistance and he goes to take the money in a Mercedes car, I was shocked, many people who are in need are prevented to have help, they treat you as a beggar."*

Outreach services were received by 26.3% of respondents, among them, more than third reported that the services were adequate and the majority reported that the services were helpful while more than half had faced a burden in seeking the services. As for the psychological services, 28.2% of respondents had received the services, and nearly the third faced burden.

Health-related sides of the child disability constituted a very high burden on caregivers who reported to agree that the medical therapy/care needed for CWD constituted a burden on HH or on caregiver with a percentage of 85%. A father who has a girl with speech, mental, mobility disability reported about the burden of medical care,

"I don't want anything in the world but to know what is the diagnosis of my child, she takes medication that can destroy a mountain and the problem is that I give her these medications and I am not sure if she is taking the right drug or not, she is always sleeping,

if I want to make exercises to her I can't, if I want to do anything to her I can't. Doctors just want to make money and feel that they satisfied the client and refer me to specific places for laboratory analysis, for medications, for another doctor, etc., I tried to go for travel abroad in MOH, they refused to give me a referral, I am thinking to leave Gaza just to know what is my daughter's case."

The highest percentage of the medical care had been provided was for medication and medical follow up with an equal percentage of 32% which compared to the Jones et al. study is in the same rank and range. A father stated about the need for medication, *"I went to many associations, I did not want money, I just want medication for my child, it is very expensive."*

Lesser than one-third of respondents had been provided with speech therapy, physiotherapy, occupational therapy, and specialized medical care while in Jones et.al study (2016), the previous services ranged from 11% to 18%. Services like assistive devices, disposables, and psychological health were provided to less than 20% of the sample respondents and this is supported by Jones et al. study with lower ranges (Jones et al., 2016). The least provided services were audiology services and orthopedic/prosthetic therapy in both, this study and Jones et al. study with less than 10% percentage. A general question was asked about receiving any service, one-third of respondents were not receiving any service and 77.5% were in need of services that not provided. When a mother of multiple disabilities asked about organizational support she noted,

"No organization provides goodness, my husband works anything any time to buy the medication needed for the child, he needs a lot of money and there is no income."

Training is an important aspect to be clarified and to identify if the caregiver is known enough to deal with the CWDs. 67% of caregivers had received training or counseling about how to deal with CWDs. This percent is generally elicited, however indicating if this training was taken ever since acquiring a disability or in the past year is followed in Table 4.12. Of respondents, more than 60% had received training on how to deal with CWDs, and counselling on basic care and dealing with health aspects. Other aspects were trained such as dealing with assistive devices and home-based care with percentages 40.5%, 56.8% respectively. Lower percentages of respondents received training in the past year with the highest received training on how to deal with CWDs (44.3%). Not far from this percentage, counseling on basic care and dealing with the health-related aspect were

reported to be trained to around 42% of respondents. A father of a child with a hearing disability stated, *"No one trained us, life trains us."* One of the key informants confirmed on the need of increasing awareness, *"We truly need to make the mothers of the normal children aware of disability, those mothers don't accept that their children sit next to a child with a mental or physical disability."*

4.1.6 Difficulties faced by caregiver related to child disability

Difficulties facing caregivers are divided into three main parts; medical care related, education-related and ADL related.

4.1.6.1 Difficulties related to child education

Table 4.13 shows that of the difficulties faced related to education, the transportation adaptation was the highest-burden that has been faced of the respondents faced difficulties related to transportation adaptation (60.7%) while Jones et al. study (2016) mentioned the percent of transportation not adapted to schools which were 27.8% and roads leading to school not adapted 34.8%. Adaptation of classroom and toilets had a low percentage of the burden faced (24.2%, 19%) respectively but was in Jones et al. (2016) 30.8%. A key informant from one of the disability-related NGOs reported regarding education difficulties one of the beneficiaries of his association faced, *"We are today in 2019, and still a wheelchair user child in a secondary school goes to his classroom held by his peers to the third floor, what is the problem if the class was in the first floor, let the teacher who wants to ease the process of teaching and go easily from class to class according to his schedule pay some effort and go up and downstairs, so what? we have school are not adopted to meet the disability needs. Kinder gardens are all special and they are plenty, but the staff is not trained or educated enough to deal with disability."* A higher percentage of respondents reported facing difficulties in educational tools adaption (31%) which is close to Jones et al. (2016) percent (27.8%). School entrance leading roads and did not pose a burden on the majority of respondents which was the least burden related to education. All the rest of types were in lesser than 30% level of burden (high burden and to some extent combined), which are resource centers such as computer lap, finding a school that enrolls CWDs, finding a school that can deal with CWDs conditions and needs, attitudes of school teachers and attitudes of peers at school which also supported with Jones et al. (2016) study.

Table (4.13): Distribution of caregiver responses related to difficulties faced due to child disability in education

Difficulties faced related to child education due to disability	Level					
	High		To some extent		Not a burden	
	No	%	No	%	No	%
Transportation adaptation	95	44.4	35	16.3	84	39.3
Classroom adaptation	17	8.4	32	15.8	153	75.7
Toilets adaptation	10	5	28	14	162	81
Educational tools adaptation	21	10.4	42	20.8	139	68.8
School entrance and exits	5	2.5	13	6.75	176	90.75
Roads leading to school	14	7.0	23	11.6	162	81.4
School playfield	4	2.2	18	9.6	164	88.2
Resource centers such as computer lap	8	6.0	26	19.6	99	74.9
Finding a school that accepts/enrolls CWDs	31	16.2	17	8.9	143	74.8
Finding a school that can deal with CWDs conditions and needs	32	16.4	17	8.7	145	75.9
Attitudes of school teachers	17	8.4	28	13.8	158	77.8
Attitudes of peers at school	23	11.9	38	19.5	133	68.5
	N		%			
If caregiver receives help in the education of CWD						
No	343		85.8			
Yes	57		14.2			
Total	400		100.0			
Who helps the caregiver in education for those who receive help						
Family members	25		45.45			
An association	14		25.45			
Special center/education school	16		29.09			
Total	55		100.0			
If CWD education constitutes a burden on you?						
No	218		54.5			
Yes	182		45.5			
Total	400		100.0			
The type of burden						
Financial	167		91.75			
Physical	119		65.38			
Forgone Opportunities	22		12.08			
Social burden	32		17.58			
Discrimination	19		10.43			
Stigma	12		6.59			

However, a mother of a multiple disability child reported about teachers' attitude, *"My child had a deformity in his foot and he always takes his shoes off, the teacher in the respected kinder garden in the middle of Gaza asked me to come to the kinder garden, she told me, dear I came here to work as a teacher not to tie you son's shoes, I went to the head of kinder garden, she said to me the interest of the teacher is above the interest of the*

student. " Another mother of a girl with visual disability reported, *"Once a teacher asked me to come to school, she complained because I asked her to bring my girl in the front desk of the class, she said to what is this curse you brought to me."*

With regard to what respondents faced in relation to CWDs education, 85.5 % of respondents had not received help in their child education, while 54.4% reported that education of their CWDs constated a burden on them., this is supported by Jones et al. (2016) study where one of the highest reasons behind stopping education among CWDs was the need for personal assistance (62.2%).

The most form of burden reported was financial with percent of 91.75% while Jones et al. (2016) (44.4%) and physical burden with a percent of 65.38% and the least was stigma with 6.5%.

A father of a 10 years old included child in one of UN schools reported, *"Our society still poor in the cultural and awareness aspects regarding disability despite the religious awareness, it is all lies, for example, my son in the third grade in the school, his peers' parents refused that their children sit near my son as if he is had scabies disease."* A mother of a girl of visual disability who suffered from stigma related to disability, gender and education of her girl she reported, *"My brother's daughter used to be the continuous companion to my daughter, she was going with my daughter everywhere, and also was going to school with her, once my daughter had an extra lesson in the school and was late, I was in a very bad case, some people started to guess and say maybe someone locked her in a bathroom, others guess many bad things, they said if she was a boy, there was no problem but the girl is a special case."*

4.1.6.2 Difficulties related to ADL

ADL burden constituted high percentages of burden. Starting from dressing the CWDs (68.28%) compared to the percentage of CWDs who can dress with difficulty according to Jones et al. (2016) which was 34.6% ranged from some to a lot of difficulties which may be attributed that this percent is for GS and West Bank and also caregivers thaught that any kind of assistance may be given to them according to their response.

The percentage of CWDs who can feed themselves with no difficulty was 71.5% according to Jones et al. (2016) which is high in relation to the burden faced reported in the study (48.8%). Getting in and out of the bed was as 43.18% percentage, while in Jones et al. (2016) the percent of CWDs who faced difficulties in getting in and out of bed (14.2%) also, moving in home (40.26%) which is lesser burden than moving outdoors (58.5%) and compared to Jones et al. (2016) where 16% of CWDs faced difficulties in moving in home and 27.1% faced in moving outdoors .

Table (4.14): Distribution of caregiver responses related to difficulties faced due to child disability in ADL

Difficulties faced in the following ADL	Level					
	High		To some extent		Not a burden	
	No	%	No	%	No	%
Dressing by him/herself	166	43.92	92	24.33	120	31.75
Feeding by him/herself	109	28.31	79	20.52	197	51.17
Getting in and out of bed	116	30.36	49	12.83	217	56.81
Bathing/washing	181	48.27	93	24.8	101	26.93
Moving about in the home	82	22.16	67	18.11	221	59.73
Moving about outdoors	126	36.31	77	22.19	144	41.5
Getting in and out of a motor vehicle (car, bus)	112	33.93	64	19.4	154	46.67
If caregiver receives help in ADL of CWD						
No	249		62.25			
Yes	151		37.75			
Total	400		100.0			
The form of help among caregivers who are receiving help						
bathing, wearing clothes, body care	43		28.46			
feeding, food preparation, laundry	27		17.9			
help in ADL	81		53.64			
Total	151		100.0			
Who helps the caregiver for those who receive help						
Association	31		19.87			
Family members	105		67.31			
relatives	20		12.82			
Total	156		100.0			

All the previous figures are consistent with the survey conducted by the National Alliance of caregiving (2009) in the U.S which reported that nearly half of caregivers of children with special needs (47%) help the child with at least one ADL.

Getting in and out of a motor vehicle constituted a considerable high burden of 53.32% and for CWDs who faced difficulty 22.2% but the highest-burden reported by the majority of respondents was bathing the CWDs with 73% percent which is supported by what CWDs reported in the Jones et al. (2016) study which was more than the half. A mother of a hyperactive child said about ADL, *"I bath my child with a miracle, and to take him to the dentist is another story, the world is upside down, no one can open his mouth, I asked the doctor to fully give him general anesthesia to treat his teeth."* Only 37.8% of respondents received help, twenty eight percent recieved help in the form of body care of the child and the majority was in the activities like dressing, getting out of bed and moving in and outdoors with 53.64%. Help was mainly given by family members (67.30%) and associations (19.87%) while help provided by family members mainly sisters and fathers reported being only 25% in Gaza according to Jones et al. (2016) study. *"A mother reported, all the people surrounding me disappointed me even my sons and daughters who are the closest to me disappointed me.*

4.1.6.3 Difficulties related to medical/healthcare

Results from Table 4.15 show that there is a significant burden related to the medical care needed to CWDs where, as mentioned before 85% of respondents agreed to having a burden attributed to medical care given to their child. Financial burden constitutes the highest type of burden faced by 97.6% of respondents while the Jones et al. (2016) study pointed that the highest out of pocket payment for many medical services (provision of disposables;88.6%, specialized medical care;60%, and medications;59.2%) (Jones et al., 2016). Also, the physical burden was faced by near two-third (60.29%). The least type faced in relation to medical care was stigma. Nearly half of the respondents did not receive any kind of help in relation to the medical care of CWDs The most form of help provided was giving the child some exercises and helping him in ADL while the least provided help was bringing medical needs and financial help. More than 60% of caregivers were prevented from doing the things that wanted to be done especially from having rest (76.3%) and housework (74.8%). While nearly half of respondents were prevented from socialization and even caring for other siblings.

As shown in Table 4.15 more than 70% of respondents reported to have difficulties in reaching the health services, availability of needed services which considered both as high percentages despite the reported percentages in the Jones et al. (2016) study where perceptions about quality of health services was reported in relation to access as 47.8% to be good and the same percent for the availability of comprehensive health services for CWDs. In contrast, the majority of respondents did not face a burden at all to have the needed support and respect from staff and this goes with the percentage of 73.4% which was reported to have good interaction with staff in the Jones et al. study (2016), but with lesser percentage, nearly two-thirds of respondents reported facing no burden at all to take the needed information about health services which is almost the same percent in the Jones et al. study (2016).

Table (4.15): Distribution of responses of caregivers by difficulties due to child disability in medical/healthcare

Difficulties faced related to the child needed health services due to disability	Level					
	High		To some extent		Not a burden	
	No	%	No	%	No	%
Reaching the health services	149	38.60	145	37.56	92	23.84
Availability of the needed services	174	45.19	128	33.25	83	21.56
Support of staff	30	8.6	60	17.19	259	74.21
Respect from staff	26	7.7	43	12.18	284	80.45
Information about health services	52	13.7	86	22.63	242	63.68
Medications	168	50.60	89	26.80	75	22.6
Counselling services	70	20.06	88	25.21	191	54.73
Medical disposals	132	47.65	66	23.83	79	28.52
Assistive devices	130	57.52	39	17.26	57	25.22
If the medical therapy/care needed for CWD constitute a burden on HH or on caregiver						
No	60		15.0			
Yes	340		85.0			
Total	400		100.0			
The type of burden						
Financial Burden	332		97.64			
Physical Burden	205		60.29			
Forgone Opportunities	41		12.05			
Social Burden	70		20.58			
Discrimination	18		5.29			
Stigma	25		7.35			
Who helps in the medical care						
None	198		49.5			
Family member	136		67.32			
Association	80		39.60			
Relatives	12		5.94			
The form of help among those receiving help						
Takes the child to sessions	28		13.9			
Bring medical needs	31		15.3			
Dressing, physical care, giving medications	25		12.4			
Financial help	9		4.45			
Giving exercises, help in ADL	55		27.22			
Provide needed therapy (physiotherapy, occupational therapy, speech, rehabilitation therapy, assistive devices, psychosocial)	54		26.73			
The things that medical care prevents caregiver from doing						
Rest	184		76.3			
House work	181		74.8			
Socialization	133		55.2			
Caring for other siblings	130		53.9			
Recreational and leisure activities	117		48.5			
Caring for other HH members	89		36.9			
Your work	28		11.6			
Education	14		5.8			
If the medical care needed for the CWD prevents from doing the things that caregiver wants to do						
No	159		39.75			
Yes	241		60.25			
Total	400		100			
If caregiver has health problems attributed to caregiving activities						
No	220		55.0			
Yes	180		45.0			
Total	400		100.0			
If caregiver receives medical care for health problem						
No	97		45.54			
Yes	116		54.46			
Total	213		100.0			

However, more than half respondents faced a high level of burden in securing medication and assistive devices (50.6%,57.5%) respectively while nearly the third (29.8%) of CWDs found that the availability of medication for them was poor according to Jones et al. (2016). Also, medical disposables were reported to be a burden on 71.47%, this goes with the Jones et al. (2016) percent of who perceived this service to be good which was less than 8%. On the other side, more than half of respondents faced no burden in counseling services while 45.2% faced burden which is the same in the Jones et al. study (2016).

Caregivers reported having health problems attributed to caregiving constituted (45%) and half of them were getting the needed medical care for their problem. When respondents were asked about the reason for not having the needed treatment, the majority said either financial difficulties or no time was available. A mother of CWD explained, *"I have been delaying my eye medication for three months because my son's medication is a priority, my eye became blue, but my child needs every week nappies and medication."*

4.1.7 Cultural Norms

The key supporters of caregivers were in the family and on the top was the partners of caregivers (84.02%) added to family members including caregiver mother and father in over than 70% percentage and siblings of CWDs especially sisters (85.3%) also teachers were from the high supporters (75.9%). Regarding the partner's family like the mother and father in law, they were moderately supportive in a percentage of around 50% of respondents. A mother with three CP children said, "*My mother in law and her sons was blaming me for the disability of my children because during my pregnancy I took heparin she used to say that I blinded my son from heparin and she made me to medically checkup by going to Jerusalem, and the investigations turned out that the problem is from her son."*.

Table (4.16): Distribution of responses of people's attitudes to the CWD with regard to disability

People support	**Disabling**		**NS/ND**		**Supporting**	
	No	**%**	**No**	**%**	**No**	**%**
Partner	26	6.7	36	9.3	326	84.0
Caregiver Mother	13	4.02	72	22.3	238	73.68
Caregiver Father	10	3.4	72	24.6	211	72.0
CWD Sisters	9	2.6	42	12.10	296	85.30
CWD Brothers	10	2.9	59	17.0	278	80.1
Other family members like aunts	48	13.4	108	30.2	202	56.4
Mother in-law	35	12.7	91	33.0	150	54.3
Father in-law	29	11.83	79	32.24	137	55.91
Peers at school/preschool	28	14.73	64	33.7	98	51.57
Neighbors	42	13.54	141	45.5	127	40.96
Teachers	14	6.5	38	17.59	164	75.92
Taxi drivers	29	12	91	37.6	122	50.4
Health providers	27	7.4	111	30.2	229	62.4
Doctors	26	7.4	110	31.2	216	61.4
Nurses	27	8.9	115	37.70	163	53.44
Salesman at shops	32	16.84	86	45.26	72	37.9
People at mosques/church	26	19.7	53	40.15	53	40.15
People at recreational places like restaurants-staff/customers	42	19.00	82	37.10	97	43.9
People help	**No**		**Somewhat**		**Yes**	
	No	**%**	**No**	**%**	**No**	**%**
Partner	124	32.0	74	19.0	190	49.0
Caregiver Mother	136	42.10	54	16.7	133	41.2
Caregiver Father	134	45.73	46	15.7	113	38.6
CWD Sisters	64	18.44	51	14.7	232	66.9
CWD Brothers	76	21.90	59	17.00	212	61.1
Other family members like aunts	188	52.51	68	18.99	102	28.5
Mother in low	139	50.4	34	12.31	103	37.3
Father in low	127	51.8	36	14.7	82	33.5
Peers at school/preschool	101	53.2	32	16.84	57	30.0
Neighbors	199	64.19	35	11.3	76	24.51
Teachers	63	29.2	36	16.7	117	54.1
Taxi drivers	137	56.14	36	14.8	71	29.1
Health providers	150	40.9	98	26.70	119	32.42
Doctors	154	43.8	80	22.72	118	33.52
Nurses	159	52.1	39	12.8	107	35.1
Salesman at shops	136	71.6	13	6.8	41	21.6
People at mosques/church	94	71.2	11	8.3	27	20.5
People at recreational places like restaurants-staff/customers	143	64.70	15	6.8	63	28.50
If services providers and or policymakers discriminate among CWD in reference to	**N**			**%**		
Reasons behind disability	137			34.6		
Age of CWD	92			23.2		
Gender of CWD	41			10.4		
Socioeconomic status	126			31.8		

Less supporting people were outside the family including neighbors, peers at school, taxi drivers, health providers, and the least supporters were people at religious places, neighbors and people in recreational places, moreover the highest disabling were the previously mentioned group of people added to salesmen in shops. A noticeable portion of the surrounding people was disabling especially from other family members like aunts (13.4%) but half of the respondents reported that those relatives were supportive but not helpful.

A mother of a learning disability child said about her child's uncle, *"My child is an orphan, and I have another boy, he destroys everything, we live with my mother in law, I hit my child every day because of them especially his uncles. They make problems with me because of my son's behaviors and because my son hits their children, they should be a big support for my son who is with half mind, they do not accept him and they always say to me take your son away and discipline him, his uncle once hit him on his face and his fingers were printed on my son's face. No one supports or bears responsibility with me."*

Jones et al. study (2016) supported the findings where mothers of CWDs were 96.4% supportive and fathers were 90.7% and as for siblings it almost matched the percentages of this study. The figures of the disabling people are supported with the call recommendations of Zuurmond et al. (2015) study which pointed to the need to address the poor communication in the family, high levels of stigma, and the need to build an effective support network for the families that have a child with a disability. As for neighbors, they were reported to be moderately supportive (40.9%) which is near to the Jones et al. (2016) where 47.1% were supportive (Jones et al., 2016).

A mother of two hearing disability children pointed out that her neighbors were disabling as she said, *"When I go to visit my neighbors, they hide their children because they are afraid of envy."*

Nearly two-thirds of respondents reported that health providers were supportive while in Jones et al. (2016) study 47.6% were supportive. In addition, doctors and nurses were moderately supportive (61.3%,53.4%) respectively, but they were much lower reported to be helpful (33.5%,35%). One mother of a child with behavioral problem explained about doctors, *"I was trying to find an accurate diagnosis among doctors for my child until a doctor diagnosed him as Autistic child and he told me that if I go all over the world, those patients need a miracle to be cured and that I should not bother myself to treat him."*

Help is provided much lesser than support where similarly it comes from inside the family. Sisters are on the top of helpers then brothers come (66.8%, 61.09%) while less than half

of caregivers' partners still helpers. A mother of a girl with physical disability confirmed, *"No one helps me except my husband when he comes back from work, but my children bring things to me because they are too young to help."* Outside the family, the highest helper was teachers (54.16%).

Discrimination according to reasons behind disability was reported by 34.6% of respondents which was the highest percentage of discrimination kinds. With lesser reported percentage, discrimination according to the age of CWDs was 23.2% while socioeconomic status was importantly reported by nearly one-third of respondents. Finally, the least percentage reported of kinds of discrimination was according to the gender of the child with only 10.3%. Jones et al. (2016) study had generally resulted that the percent of CWDs who felt that community discriminates against them sometimes was 26%, frequently 28.2% and always 17.1%. These figures support the results of this study.

4.1.8 Reasons for not receiving services

It has been necessary to spotlight the financial burden and give it that space not just because of the very difficult economic situation in Gaza but also, because of the sequences of disability and multiple needs that may disturb the financial safety of the family as a whole. This domain describes the services that required and not received for caregivers and describes the reasons behind not receiving the service which appeared to be most of the time related to financial problems. The percentage of respondents who did not receive the services because of financial difficulties was more one third for receational services and transportation but for health services, rehabilitation services, and educational services were reported to be around 15%. The recreational services that are not impeded in the Gazan culture, it was required from 56.3% of the respondents which is considered a high percent while the percent of facing difficulties to secure these services was 21.1% according to Jones et al. (2016). Moreover, supporting this financial hardship resulted in this study, there were more than 80% HH in Gaza who faced financial difficulties because of the expenses of disability of their child (Joes et al., 2016). Basic services like health services were requested by 49.1% of respondents. A father of a multiple disabilities girl said about health needs, *"My daughter consumes more than three fourth of my salary and I am an employee there are many requirements in relation to income, the day she was born the house system turned upside down."* Regarding transportation which was reported to be required and not received by 47.3% while more than half CWDs families found difficulties to secure transportation (Joes et al.,2016), A mother of visual disability child said, *"My*

son needs glasses and medications, for 6 months I have been saying that I am going to buy him the glasses the next month, I need transportation to go, money to pay for the doctor, even I asked the salesman to pay for the glasses as installments, but now I can't." While a key informant confirmed, *"Our services are for free but the only thing the families contribute in is transportation, the association do not have cars or buses to bring them, this resulted in that the residents in Gaza are the only beneficiaries from our services, its costly for other governorate residents to come even if its free services.*

Table (4.17): Distribution of responses of caregivers reasons for not receiving services

Services / **Reasons for not receiving service**	**Number/Percent**	**Recreation**	**Health /medical services**	**Transportation**	**Rehabilitation services**	**Education services**	**Language/ Audiology services**	**Provision of disposables**	**Psychological /mental health**	**Social assistance**	**Assistive devices`**
Financial difficulties	**N**	150	75	127	49	61	63	60	25	71	60
	%	38.4	19.2	32.5	12.5	15.6	16.1	15.3	6.4	18.2	15.3
Lack of the service	**N**	18	28	16	42	14	22	19	26	81	20
	%	4.6	7.2	4.1	10.7	3.6	5.6	4.9	6.6	20.7	5.1
Don't know where to go	**N**	15	7	13	11	14	17	12	31	113	6
	%	3.8	1.8	3.3	2.8	3.6	4.3	3.1	7.9	28.9	1.5
Inadequate N of org.	**N**	9	11	24	37	19	19	16	15	36	15
	%	2.3	2.8	6.1	9.5	4.9	4.9	4.1	3.8	9.2	3.8
long waiting lists	**N**	2	15	1	3	2	5	4	5	9	26
	%	0.5	3.8	0.3	0.8	.5	1.3	1	1.3	2.3	6.6
Poor quality of services	**N**	1	15	3	4	19	7	3	9	1	6
	%	0.3	3.8	0.8	1	4.9	1.8	.8	2.3	.3	1.5
Social barriers	**N**	11	2	2	5	2	2	1	13	0	0
	%	2.8	.5	0.5	1.3	.5	.5	.3	3.3	0	0
Physical accessibility barriers	**N**	3	2	2	6	10	5	1	2	0	2
	%	0.8	0.5	0.5	1.5	2.6	1.3	.3	.5	0	.5
Not medically insured	**N**	1	1	0	1	0	1	0	0	1	2
	%	0.3	0.3	0	0.3	0	.3	0	0	.3	.5
Total	**N**	220	192	185	157	156	139	138	132	288	143
	%	56.3	49.1	47.3	40.2	39.9	35.5	35.3	33.8	73.7	36.6

As for rehabilitation services, it was reported by 40.2% of respondents and according to Jones et al. (2016) more than two-third found difficulties in securing transportation. As Table 4.17 shows educational services were required by a lesser percent of caregivers (39.9%). The services following were required by respondents in percentages of speech/language services (35.5%), provision of disposables (35.3%), and assistive devices services (36.6%), compared to Jones et al. (2016) lower figures were reported for speech/language therapy with 26.2% needed, 9.5% for needed disposables provision. The

reasons for not receiving all of these services were the same but with different reporting percentages but all the percentages were around 15% for financial difficulties. The highest required services were social assistance services (73.7%) with a different ranking of reasons behind not receiving them. Obviously, the main cause reported was not knowing where to go (28.9%), secondly lack or unavailability of services (20.7%). On the other hand, the least required services were psychological services (33.8%) because of not knowing where to go (7.9%). Supporting the results of the study, the National Alliance for caregiving in the U.S (2009) reported that caregivers of children are more likely to feel at least some financial hardship as a result of caring for their loved one than their counterparts who care for an adult, and twice as likely to feel strong financial hardship. One in three of caregivers of children has sought financial assistance on behalf of the child (32%). It is worth mentioning that Al-Dujaili &Al-Mossawy (2017) had pointed to the association between the levels of the psychosocial burden of caregivers and monthly income. The results revealed that there was a significant relation between psychosocial burdens among caregivers of ASD children with respect to monthly income.

Moreover, 89.1% of caregivers reported agreeing that disability exhausted them financially as shown in Figure 4.4.

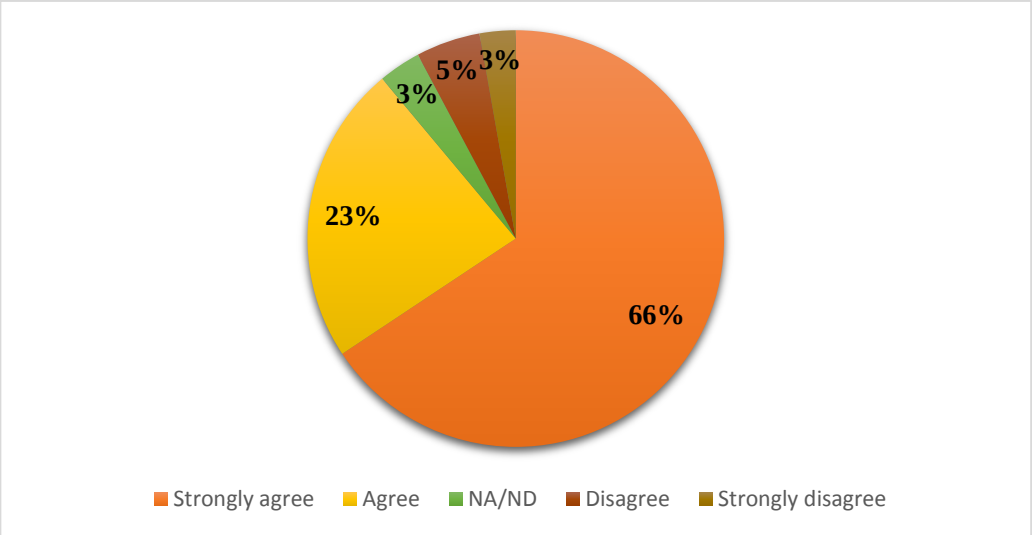

Figure (4.4): Caregiver responses on financial exhaustion due to disability

4.1.9 Forgone opportunities

In this domain, the focus is on the extent the study respondents lost opportunities they would have liked to have but they could not due to disability. Also, this domain shows how siblings were affected by the presence of disability in the family. Difficulties faced by

caregiver due to disability were varied, socially 59.7% of respondents experienced forgone opportunities in mixing with other people, going with this percentage 63.5% had lost opportunities to socialize with others, similarly 63.2% had lost opportunities to attend social events. All these figures are supported by the National Alliance for caregiving (2009) figures where six out of ten caregivers of children (60%) said their caregiving limited the amount of time they spend with other family and friends. On the other hand, only one third faced difficulties in hosting people. Unlike the Jones et al. (2016) percentage of forgone opportunities to socialize with others for HH members which was one forth faced difficulties, the percentages of this study appeared to be higher which maybe because it is reported by the caregivers themselves and not the CWDs or any family member (Jones et al., 2016).

Table (4.18): Distribution of responses by forgone opportunities

Forgone opportunities experienced by the caregiver because of the disability of the child	**N**	**%**
Difficulties in securing recreational activities	301	75.25
Difficulties to have leisure activities	299	74.75
Forgone opportunities to socialize with others	254	63.5
Difficulties in attending social events	253	63.25
Difficulties mixing with other people	239	59.75
Difficulties in hosting people	144	36
Difficulties in enrolling in education	68	17
Difficulties in finding a job	58	14.5
Difficulties in keeping a job	35	8.75
Forgone opportunities experienced by siblings		
Decreased Care from father/mother	203	50.7
Lost recreational activities	183	45.8
Lost socialization	177	44.3
Lost needs	176	44.0
Lost education	156	39.0
Not applicable	109	27.3

A noticeable low percentage of respondents reported to face difficulties in finding a job or keeping a job (14.5%, 8.7%) and for Jones et al. (2016), the percent was as low as 6% to face difficulties (Jones et al., 2016) and when the caregivers were asked about this low percent they said that working was not even an option from the day this child existed, which explained that the majority reported to not applicable in these questions. This is supported by the National Alliance for caregiving (2009) figures where 21% gave up their work entirely. As for education forgone opportunities, it was reported that 17% had faced difficulties to enroll in education.

A mother of a Down syndrome reported in tears, *"I had 85% in tawjihi, I was married then and when brought my son they told me to forget education, you cannot bear it, I wished to become a nurse. All the girls in my age became teachers or when I go to the clinic to treat my son and I find that my colleague takes the blood sample, they told me how could you go to learn and leave your sick son."*

Leisure and recreational activities were reported to be the highest percentages among all where the chance of enjoying self is the lowest with (75.2%, 74.7%) while for Jones et al. (2016) the percent was 21% reported to have difficulties in having recreational opportunities (Jones et al., 2016).

Siblings had been reported by respondents to experience forgone opportunities due to the presence of disability in the family where priorities changed since disability had come. A brother of four physical disabilities said, *"I wish to have a bicycle if my siblings do not exist my father may have the ability to buy it for me. every time I ask him to buy it for me, he says ok but when god eases it."*

The highest percentage of respondents said that siblings faced decreased care from caregivers with 50.7%. lost education was reported by 39%, lost recreational activities, lost socialization and lost needs, all were going with each other of a percentage of more than 40%. A mother of a child with a physical disability and had a dead child with CP confirmed how siblings were affected, *"The brothers and sisters of Mohammed thought of their brother and remember their sister and expect what is going to happen with their brother, they carry responsibility where no going out or leisure. their studying was affected, no relationships, I feel injustice towards my children and there is always a missing thing, I feel that I am not securing them."* A father of a CP child also reported about siblings, *"His siblings feel jealous of their brother because I care a lot for him and many times, they blame me and their mother and say why did you bring him to this life we hope that he dies."*

4.1.10 Psychsocial burden

This domain is to clarify the extent to which the psychosocial factors could have an impact on the caregiver's QoL. Results from Table 4.19 show a group of social and psychological aspects relating to the caregiver points of view which reveals that more than half of respondents found difficulty in dealing with their child and less than one third did not. New relationship forming was affected due to caring for the child disability as reported by nearly half the respondents but more than one-third of respondents reported that child disability did not have an effect on forming new relationships.

Table (4.19): Distribution of responses of caregivers by the social burden

Item	Strongly agree		Agree		Neutral		Disagree		Strongly disagree	
	No	%	No	%	No	%	No	%	No	%
The caregiver finds difficulty in dealing with CWD	55	13.75	174	43.5	68	17.0	68	17.0	35	8.75
The child's disability has an effect on not forming a new relationship	36	9.0	151	37.75	68	17.0	110	27.5	35	8.75
The child disability makes caregiver feel alone and isolated	27	6.75	91	22.75	61	15.25	164	41.0	57	14.25
The caregiver feels worried about the future	177	44.25	127	31.75	26	6.5	39	9.75	31	7.75
The caregiver feels ashamed because of the child disability	13	3.25	41	10.25	40	10.0	216	54.0	90	22.5
The negative attitude of the society creates psychological problems for caregiver	96	24.0	125	31.25	36	9.0	110	27.5	33	8.25
The caregiver ambitions were broken because of the child disability	32	8.0	73	18.25	85	21.25	150	37.5	60	15.0

More than half (55.2%) of the respondents believed that child disability did not make them feel alone and isolated but nearly one third believed that disability did. A mother of an autistic child talked about social isolation, *"I don't take my child to visits, he is destructive and embarrasses me so I hide him from society, he turned to be extremely introverted and isolated, and that was a mistake, I was dying thousand times a day when anyone asked me about him and why I did not bring him, the society is ruthless."*

Additionally, the majority of respondents (76.1%) had worries about the future. A father of a girl with multiple disabilities said about his worries, *"I always hear from people that my*

daughter's future is destroyed, even from the closest people around you, I once kicked my sister out of my home because she said so."

In contrast to previous results, 76.5% of the respondents did not feel ashamed because of child disability. Despite that, more than half of caregivers felt that the negative attitude of the society created psychological problems for them but around one-third of them did not feel that. In the study of Ngo et al. (2012) which focused on stigma and restrictions in social life of families of ID children a scale to measure stigma was developed (Restriction of Social Life Scale) scores on the scale indicated a range 4–12, with the average respondent reporting at the high end of the scale, indicating substantial restrictions on social life, mothers reported slightly more social stigma (mean= 10.0; median=11.0) than fathers (mean= 9.6; median= 9.0), the previous findings was agreeing with some of the figures of the study like the negative attitudes of society that created psychological problems for caregiver which reported to be agreed with more than half the respondents as mentioned earlier. More than half of the respondents disagreed that their ambitions were broken because of child disability while 26.3% agreed.

4.1.11 Time use

4.1.11.1 Caregiver general time use

This domain provides data that allow distinguishing between various components of a full day (24 hours). It also indicates paid work (formal, informal, subsistence) and unpaid work (unpaid domestic services, care work, housework), as well as various components of leisure and cultural activities (sports, hobbies, culture, mass media), and finally, time spent for satisfying physiological needs (sleeping, eating, self-care, etc.).

Table 4.20 shows that caregivers were spending time on a wide variety of activities, so the majority spent a time of an hour or less of each activity except the activities of sleeping, food preparation and clean up and caring for HH members or HH children. An autistic child-mother reported about her day, *"Every day I wake up on a disaster made by my son, sometimes a noise of breaking something, sometimes I find him wearing the whole closet and of course it is in a mess, I need at least two hours to just pick up after his disasters."*

Table (4.20): Distribution of responses of caregivers by general time use

Activity	Less or equal one hour		1.1-3 hours		3.1-6 hours		6.1-9.9 hours		More or equal 10 hours		Mean
	No	%	No	%	No	%	No	%	No	%	
Sleeping	2	.5	16	4	212	53	161	40.3	9	2.3	3.39
Eating and drinking	384	96	16	4	0	0	0	0	0	0	1.04
Housework	62	15.5	228	57	68	17	8	2	34	8.5	2.31
Food preparation and cleanup	171	42.8	220	55	9	2.3	0	0	0	0	1.59
Purchasing goods and services	304	76	2	.5	0	0	0	0	0	0	1.24
Professional and personal care services	363	90.8	31	7.8	4	1	2	.5	0	0	1.11
Caring for and helping HH members	195	48.8	147	36.8	34	8.5	12	3	12	3	1.74
Caring for and helping HH children	165	41.3	144	36	65	16.3	20	5	6	1.5	1.89
Caring for and helping non-HH members	374	93.5	22	5.5	4	1	0	0	0	0	1.07
Working	347	86.8	21	5.3	20	5	12	3	0	0	1.24
Educational activities	323	80.8	59	14.8	17	4.3	0	0	1	.3	1.24
Attending class	359	89.8	41	10.3	0	0	0	0	0	0	1.10
Homework and research	385	96.3	14	3.5	1	.3	0	0	0	0	1.04
Religious and spiritual activities	367	91.8	32	8	1	.3	0	0	0	0	1.08
Leisure and sports	381	95.3	17	4.3	2	.5	0	0	0	0	1.05
Socializing and communicating	269	67.3	118	29.5	13	3.3	0	0	0	0	1.36
Watching television	292	73	102	25.5	6	1.5	0	0	0	0	1.28
Participating in sports, exercise, and recreation	391	97.8	9	2.3	0	0	0	0	0	0	1.02
Telephone calls, mail	347	86.8	46	11.5	7	1.8	0	0	0	0	1.15

With a mean of 3.39 hours of sleep, sleeping consumed 3.1 to 6 hours a day for more than half of respondents and 6.1 to 9.9 hours for 40.3% of respondents compared with average Palestinian woman personal care and maintenance which included rest and sleep where consumed more than half of the day which indicates how much lost time of rest and sleep caregivers experience. (Charmes, 2015). As shown in Figure 4.5 time of rest, sleep and leisure combined together (mean=3.7) was reported that 55% of respondents spend between 6.1 to 9.9 hours on this activity. Only an hour or less was consumed on many activities in different percentages where eating and drinking (96%), caring for and helping HH members (48.8%), caring for and helping HH children (41.3%), socializing and

communication (67%), Watching television (73%), food preparation (42.8%) and with more than 85% of activities like participating in sports, exercise, and recreation and Telephone calls, mail, and e-mail.

While other activities like caring for and helping HH members took more time where 3.1to 6 hours were spent by 36.8%, and caring for and helping HH children by 16.3%. Compared by an average woman who spends 20% of her day on social life and leisure while men spend 35% (Charmes, 2015).

Going with the previous finding, Luijkx, Van der Putten & Vlaskamp (2017) study concluded that a significant amount of time has to be spent by parents on care and have an average 1.5 less free time per day than parents of typical children, and referred that this conclusion is striking because of the important contribution of leisure time to wellbeing.

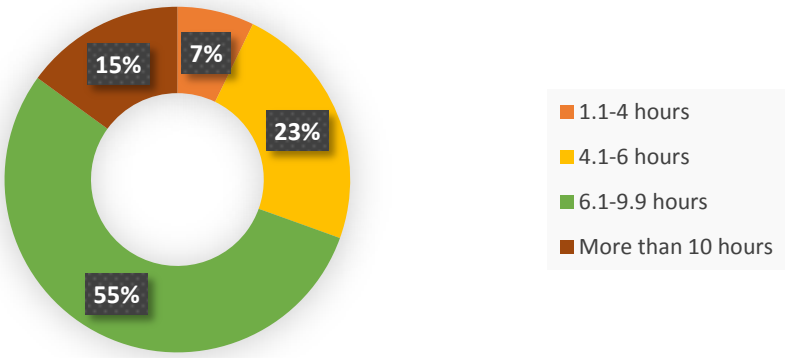

Figure (4.5): Time spent by caregivers on rest and leisure including sleep

In contrast to the previous activity, housework consumed more time with 57% of respondents spent from 1.1 to 3 hours and 55% spent on food preparation. Another mother of behavioral problem child reported, *"I do not do anything except watching out my child, he can injure himself, he had previously been lost, I call my husband every day crying especially during exams of my other kids, sometimes I cannot give him his medication, he refuses to be around his siblings, all my time is with him."*

Activities of purchasing goods and services, professional and personal care services, working, educational activities, attending class, homework, and research, religious and spiritual activities, leisure and sports, all had not consumed a lot of time according to more than 80% of respondents compared to average woman unpaid work consumes 20% of her time while in men only 9% of his time spent on unpaid work which includes caregiving (Charmes, 2015).

4.1.11.2 Time adults spent caring for HH children

A real comparison between parents in terms of how much time they spend caring for their CWDs and siblings is presented in this domain.

Table (4.21): Distribution of responses by time adults spent caring for household children in hours

Activity	Less or equal one		1.1-3		3.1-6		6.1-9.9		More or equal 10		Mean
	No	%	No	%	No	%	No	%	No	%	
Mother time spent on CWD											
Caring for HH child	121	30.25	113	28.25	95	23.75	34	8.5	37	9.25	2.3825
Physical care	330	82.5	49	12.25	16	4	4	1	1	.25	1.2425
Education-related activities	323	80.75	62	15.5	12	3	3	.75	0	0	1.2375
Reading to/with child	371	92.75	19	4.75	6	1.5	4	1	0	0	1.1075
Talking to/with child	215	53.75	73	18.25	82	20.5	11	2.75	19	4.75	1.8650
Playing/doing hobbies with children	336	84	55	13.75	6	1.5	1	.25	2	.5	1.1950
Looking after child	158	39.5	113	28.25	65	16.25	25	6.25	39	9.75	2.1850
Attending child events	339	84.75	55	13.75	6	1.5	0	0	0	0	1.1675
Father time spent on CWD											
Caring for HH child	308	78	42	10.6	29	7.34	14	3.54	2	.51	1.4070
Physical care	383	96.96	9	2.28	3	.76	0	0	0	0	1.0528
Education-related activities	390	98.74	4	1.01	1	.25	0	0	0	0	1.0226
Reading to/with child	388	98.23	5	1.27	1	.25	1	.25	0	0	1.0352
Talking to/with child	330	83.54	27	6.84	38	9.62	0	0	0	.0	1.2839
Playing/doing hobbies with child	371	93.92	21	5.32	3	.75	0	0	0	0	1.0829
Looking after child	335	84.81	27	6.84	27	6.84	6	1.51	0	0	1.2739
Attending child events	393	99.5	2	.50	0	0	0	0	0	0	1.0151
Mother time spent on siblings											
Caring for HH children	147	38.29	131	34.11	78	20.31	17	4.43	11	2.86	1.9948
Physical care	305	79.42	63	16.40	10	2.60	3	.79	3	.79	1.2708
Education-related activities	262	68.23	107	27.87	14	3.64	1	.26	0	0	1.3594
Reading to/with children	332	86.46	48	12.5	4	1.04	0	0	0	0	1.1458
Talking to/with children	243	63.28	57	14.84	69	17.97	2	.52	13	3.39	1.6589
Playing/doing hobbies with children	342	89.06	34	8.85	8	2.09	0	0	0	0	1.1328
Looking after children	197	51.30	102	26.57	46	11.98	7	1.82	32	8.33	1.8932
Attending children's events	342	89.06	39	10.16	2	.52	1	.26	0	0	1.1198
Father time spent on siblings											
Caring for HH children	311	81.41	45	11.79	19	4.97	3	.79	4	1.04	1.2827
Physical care	378	98.95	4	1.05	0	0	0	0	0	0	1.0105
Education-related activities	368	96.33	14	3.67	0	0	0	0	0	0	1.0366
Reading to/with children	378	98.95	4	1.05	0	0	0	0	0		1.0105
Talking to/with children	317	82.98	29	7.59	31	8.11	3	.79	2	.52	1.2827
Playing/doing hobbies with children	356	93.19	23	6.02	2	.52	0	0	1	.26	1.0812
Looking after children	324	84.82	35	9.17	14	3.66	1	.26	8	2.09	1.2565
Attending children's events	381	99.74	1	.26	0	0	0	0	0	0	1.0026

Table 4.21 shows data on time spent by a caregiver who was 95% of the mother in different activities. Activities like reading with the child, attending child events, physical care, education related activities and playing with CWDs were reported by the majority of respondents to be less consuming where they consumed an hour or less, while other activities like caring for HH CWD, talking with him, looking after him were more time consuming and reported by around 20% of respondents to take from 3 to 9 hours.

On the other hand, the majority of fathers spent a very much shorter time for CWDs and siblings as much as an hour or less on most of the activities, however, talking with the CWD was considering taking more time as 9.6% of fathers spent from 3.1 to 6 hours talking with their CWDs. As for siblings, around two-third of mothers spent an hour or less on most of the activities but caring for HH children, looking after them, and educational activities took more time up to 3 hours. Moreover, a low percentage of father spend more than hour in any activities A father confirmed, "*All of us confess that most of the work and caring is performed by mothers when they ask us to help them or the teach our children, we say "I feel bored, I am going to see my friends.* A mother of a visual disability child said, *"I spend half of my day with my son in the school, I go with him every day, he is in his first grade and he is trying to cope, I feel afraid that a child hit him or he hits a wall or fall down during the break time."* A mother of four children with visual disabilities said, *"My oldest daughter was complete blind, as she gets older the responsibility becomes bigger, I read all her books to her and with every level the number of books increases and becomes more difficult, adding to the other responsibilities towards her brothers, and home also their father is with physical disability, he has needs, all my day is for them"*

4.2 Inferential analysis

The inferential analysis is made to examine variations in the wellbeing among caregivers of CWDs in reference to characteristics such as gender, level of education, geographical distribution, income, etc., and disability-related variables such as type of disability in addition to the correlation between wellbeing and PSI. Moreover, to examine variations in PSI among caregivers of CWDs in reference to demographic characteristics of caregiver and CWDs like age, governate, income, etc. also variations related to disability characteristics. Furthermore, an interesting correlation with time use, wellbeing, and PSI.

4.2.1 Differences in overall wellbeing in relation to demographic characteristics

Results from Table 4.22 show that there are statistically significant differences in the overall wellbeing across governorates (P-value = 0.0001) according to ANOVA test with the highest mean of Rafah (mean=3.5) and the lowest (mean=2.67) in Middle governorate and the LSD test shows that statistically significant differences occurred between Rafah and Middle governorate and all other groups.

Table (4.22): Differences in overall wellbeing in relation to demographic characteristics

Independent variables		**N**	**Mean**	**SD**	**Factor**	**Value**	**Sig.**
Governorate	North	94	2.9288	.59975	**F**	19.274	.0001
	Gaza	117	2.9744	.55200			
	Middle	59	2.6734	.58906			
	Khanyonis	83	3.0148	.34703			
	Rafah	47	3.5876	.65122			
Age	20-30	131	3.0863	.55816	**F**	2.076	.127
	31-40	171	2.9597	.63178			
	41or more	98	2.9537	.57058			
Refugee status	refugee	265	3.0171	.62996	**t**	.819	.413
	Non-Refugee	135	2.9655	.52113			
Education	Secondary or less	305	2.9705	.57807	**t**	-1.625	.106
	Diploma or more	94	3.0912	.64482			
Family type	Nuclear family	319	3.0404	.60103	**t**	2.893	.004
	Extended family	81	2.8395	.54677			
Average HH monthly income from all source… (NIS)	Less than 800	162	2.9601	.57364	**F**	5.371	.005
	801-1500	81	3.1073	.59119			
	More than 1500	20	3.3788	.66866			

Moreover, the overall wellbeing in relation to age indicated no statistically significant variance (P-value = 0.127) with the lowest age group in relation to QoL which was the group aged above 41 years with mean=2.95. In addition, Table 4.22 shows no statistically significant variance between refugees and non-refugees (P value=0.413) with higher mean in refugee respondents.

Despite that result in Table 4.22 shows that there are no statistically significant differences in overall wellbeing in relation to educational level (P-value =0.106), but the mean is slightly higher of respondents who were higher educated. Furthermore, the family type has been grouped into two groups; extended families where members other than father, mother sons, daughters were living at the same place and nuclear families where father, mother sons, daughters were living together. The overall wellbeing was then tested in relation to

family type using the t-test. Results from Table 4.22 show that there was a statistically significant difference between the two groups (P-value = .004), where members of smaller families reported higher levels of satisfaction about their lives (mean = 3.01) than members of larger families (mean = 2.8). In addition to the lower impact of economic hardships when the family size is smaller, members of small families could feel more satisfied because of better housing conditions (e.g. space and privacy for the family members).

The study findings as listed in Table 4.22 indicate a positive association between income and satisfaction about the QoL. People whose income was less than NIS 800 were less satisfied (mean = 2.9) and those with higher income were more satisfied (mean = 3.10). When income reached (NIS 1500 and more) the mean increased to 3.37. ANOVA test indicated a statistically significant variance between respondents in reference to their HH income (P-value = .005). The LSD test shows that statistically significant differences occurred between the group of more than 1500 NIS income and the least income group with less than 800. Similar to this study, a substantial correlation was concluded between the average per capita and average wellbeing indicating that wealthier nations are happier. In that sense, income positively correlates to wellbeing (Diener, 2009).

4.2.2 Differences in overall wellbeing in relation to disability characteristics

The nature of disability could logically affect the QoL despite the results in Table 4.23 which indicates that there is no statistical significance in relation to the nature of disability (P-value =0.113). The results show that wellbeing means are quietly different, for instance, the lowest mean of wellbeing was the Behavioral disability (mean =2.8) while surprisingly the multiple disabilities type showed the highest mean (mean=3.16). Child characteristics such as gender did not show statistically significant (P-value=0.286) but there is a slight difference in means of wellbeing among caregivers of males than females in the favor of males. (male mean=3.01, female mean=2.9). Despite the previous results, the qualitative FGs showed the differences according to age, for instance, a father of a spastic CP child reported, *"Of course, it would make a difference if I had a boy, the boy is stronger to face life, but the girl is weak, she will not marry, and people look in a bad way at her and at the family, they made me deny that there was anything wrong with her so as to protect her and her sisters, people believe that disability is always related to hereditary."*

Table (4.23): Differences in overall wellbeing in relation to disability characteristics

Independent variables		N	Mean	SD	Factor	Value	Sig.
Nature of disability	Visual	60	3.0635	.54594	F	1.796	.113
	physical	77	3.0534	.59379			
	Behavioral	52	2.8107	.60530			
	hearing and speech	64	2.9754	.65524			
	learning and cognitive	71	2.9512	.57288			
	Multiple disabilities	76	3.1677	.59969			
Gender of child	Male	207	3.0305	.57176	t	1.067	.286
	Female	193	2.9667	.61934			
Age of the child	1-4	94	3.1297	.54946	F	3.030	.029
	4.1-6	56	2.9437	.58500			
	6.1-10	119	3.0323	.60627			
	10.1-18	131	2.9008	.60734			
Having other PWDs or CWDs	Yes	122	2.9098	.59430	t	-2.006	.046
	No	278	3.0392	.59250			
Number of HH members	3-6	149	3.0490	.57405	F	8.546	.0001
	7-10	191	3.0516	.61003			
	more than 10	60	2.7122	.52213			
Number of Children under 18	1-3	155	3.0479	.58606	F	1.481	.229
	4-7	229	2.9807	.59947			
	8-15	16	2.8053	.60675			
% of expenditures spent on needs of CWD	less or equal than 30	127	3.0778	.65870	F	4.743	.009
	31-50	146	3.0419	.56566			
	51-80	115	2.8589	.54220			

Unlikely the gender variable, there was a statistically significant difference between caregivers who have another person or CWD or not (P-value=0.046), where there was an obvious difference in means, where having other people or CWDs in HH had a lower mean (mean =2.9) than caregivers who had not(mean=3.03) also, the age of the child showed statistical difference with the lowest mean of the oldest group (P-value=0.029). The LSD test shows that statistically significant differences occurred between the youngest and the oldest group .Similarly, the number of HH members showed a statistical significance (P-value =.0001) with the lowest mean in a higher number of HH members where HH with more than 10 members had the lowest mean(mean=2.7). Although the number of children did not show statistical significance (P-value =0.229) but the more children in HH, the lower the mean; more than 10 children in HH group had the lowest mean (2.80). The LSD test shows that statistically significant differences occurred between the group of more than 10 HH members and the other groups.

The percentage of expenditure on the CWDs in relation to income showed a statistical significance (P-value =.009) with a mean difference between groups in the favor of lower

percentage where expenditure between 51% and 80% showed the lowest mean of (2.8). The LSD test shows that statistically significant differences occurred between the group with the highest percent of expenditure and the other two groups.

4.2.3 Differences in overall PSI in relation to demographic characteristics

t-test, ANOVA, correlation tests have been applied to examine variations in PSI among caregivers. Results from Table 4.24 shows that there are statistically significant differences in the overall PSI across governorates (P-value = 0.0001) according to the ANOVA test with the highest mean of Rafah (mean=3.58) and the lowest (mean=2.55) in Gaza.

Table (4.24): Differences in overall PSI in relation to demographic characteristics

Independent variables		**N**	**Mean**	**SD**	**Factor**	**Value**	**Sig.**
Governorate	North	94	2.6189	.54613	**F**	54.038	.0001
	Gaza	117	2.5522	.46638			
	Middle	59	2.6725	.50747			
	Khanyonis	83	2.6936	.49788			
	Rafah	47	3.5876	.65122			
Age	20-30	131	2.7312	.60467	**F**	.478	.620
	31-40	171	2.7604	.69434			
	41or more	98	2.8167	.66550			
Refugee status	refugee	265	2.8228	.69815	**t**	2.491	.013
	Non-Refugee	135	2.6505	.55674			
Education	Secondary or less	305	2.7596	.68134	**t**	.693	0.395
	Diploma or more	94	2.7903	.57655			
Family type	Nuclear family	319	2.8206	.67110	**t**	3.422	.001
	Extended family	81	2.5441	.55571			
Average HH monthly income from all sources (NIS)	Less than 800	162	2.6947	.67381	**F**	5.969	.003
	801-1500	81	2.8779	.67847			
	More than 1500	20	3.2018	.71168			

The LSD test shows that statistically significant differences occurred between Rafah and all the other governorates. Moreover, the overall PSI in relation to age indicated no statistically significant variance (P-value = 0.620) with the highest age group in relation to PSI which was the group aged above 41 years with mean=2.8. In addition, Table 4.24 shows statistically significant variance between refugees and non-refugees (P value=.013) with higher mean in refugee respondents (mean=2.8).

Despite that result in Table 4.23 shows that there are no statistically significant differences in overall PSI in relation to educational level (P-value =0.395), but the mean is slightly higher of respondents who were higher educated. Furthermore, the family type has been grouped into two groups; extended families where members other than father, mother sons,

daughters were living at the same place and nuclear families where father, mother sons, daughters were living together. The overall PSI was then tested in relation to family type using the t-test. Results from Table 4.24 show that there was a statistically significant difference between the two groups (P-value = .001), where members of smaller families reported higher levels of parental stress (mean = 2.8) than members of larger families (mean = 2.5). In addition to the lower impact of economic hardships when the family size is smaller, members of small families could feel less stressed because of better housing conditions (e.g. space and privacy for the family members). The study findings as listed in Table 4.24 indicate a positive association between income and overall PSI. People whose income was less than NIS 800 were more stressed (mean = 2.6) and those with higher income were lesser stressed (mean = 2.8). When income reached (NIS 1500 and more) the mean increased to 3.20. ANOVA test indicated a statistically significant variance between respondents in reference to their HH income (P-value = .003). The LSD test shows that statistically significant differences occurred between the least income group of lesser than 800 NIS and all the other groups.

4.2.4 Differences in overall PSI in relation to disability characteristics

The nature of disability had a statistical significance in relation to parental stress as results shown in Table 4.25 (P-value =.0001). The results also show that overall PSI means were different among types of disability, for instance, the lowest mean of PSI was the behavioral disability (mean =2.5) while surprisingly the multiple disabilities type showed the highest mean (mean=3.1). The LSD test shows that statistically significant differences occurred between all groups where visual disability showed statistical differences among all groups except hearing and speech disability while the later showed statistical differences with all groups except the visual disability.

Child characteristics such as gender and age of the child did not show statistically significant (P value=0.475,0.151) but there is a slight difference in means of PSI among caregivers of males than females in the favor of males. (male mean=2.74, female mean=2.78). Similarly, the gender variable did not show a statistical significant difference between caregivers who have another person or child with disability or not (P-value=0.161), where there was a slight difference in means, where having other people or CWDs in HH had lower mean (mean =2.6) than caregivers who had not (mean=2.7).

Table (4.25): Differences in overall PSI in relation to disability characteristics

Independent variables		N	Mean	SD	Factor	Value	Sig.
Nature of disability	visual	60	3.0929	.70334	**F**	6.753	.0001
	physical	77	2.7217	.65722			
	Behavioral	52	2.5227	.59502			
	hearing and speech	64	2.9492	.65909			
	learning and cognitive	71	2.6247	.58634			
	Multiple disabilities	76	3.1677	.59969			
Gender of child	Male	207	2.7419	.61057	**t**	-.716	.475
	Female	193	2.7890	.70654			
Age of the child	1-4	94	2.8492	.67014	**F**	1.775	.151
	4.1-6	56	2.6046	.56612			
	6.1-10	119	2.7971	.72534			
	10.1-18	131	2.7429	.61455			
Having other PWD or CWDs	Yes	122	2.6941	.67155	**t**	-1.405	.161
	No	278	2.7956	.65108			
Number of HH members	3-6	149	2.7069	.61527	**F**	9.011	.0001
	7-10	191	2.8906	.68363			
	more than 10	60	2.5071	.58996			
Number of Children under 18	1-3	155	2.7470	.61056	**F**	.244	.784
	4-7	229	2.7820	.67821			
	8-15	16	2.6875	.83161			
% of expenditures spent on the needs of CWD	less or equal than 30	127	2.9916	.72360	**F**	13.416	.0001
	31-50	146	2.7099	.66457			
	51-80	115	2.5752	.50714			

Unlikely, the number of HH members showed a statistical significance (P-value =.0001) with the lowest mean in a higher number of HH members where HH with more than 10 members had the lowest mean (mean=2.5). The LSD test shows that statistically significant differences occurred between all three groups. Although the number of children did not show statistical significance (P-value =0.784), but the more children in HH, the lower the mean; more than 10 children in HH group had the lowest mean (2.6).

The percentage of expenditure on the CWDs in relation to income showed a statistical significance (P-value =.0001) with a mean difference between groups in the favor of lower percentage where expenditure between 51% and 80% showed the lowest mean of (2.5). The LSD test shows that statistically significant differences occurred between the least percent group with less than 30% and all other groups.

4.2.5 Correlations of QoL

4.2.5.1 Wellbeing correlation with PSI

Table 4.26 shows the results of examining the relationship between wellbeing and PSI by performing the Pearson correlation test as shown below. The correlation test showed a positive correlation between parental stress and wellbeing as indicated in Figure 4.6 (r = 0.589) at a statistically significant value of difference (P-value = 0.001).

Table (4.26): Correlations of QoL

Variable	r	P-value
Correlation between Overall wellbeing and overall PSI		
Overall wellbeing	.589**	.001
Total PSI	.589**	
Age of CWDs correlation with overall wellbeing and PSI		
Overall wellbeing	-.125*	.012
Overall PSI	-.032	.520
Rest and leisure time correlation with wellbeing and PSI		
Overall QoL	-.125*	.012
Overall PSI	-.032	.520

**. Correlation is significant at the 0.01,0.05 level (2-tailed).

Figure 4.6 shows that the correlation between overall parental stress and overall wellbeing resulted in a linear ascending line (positive correlation). The correlation is considered of high strength.

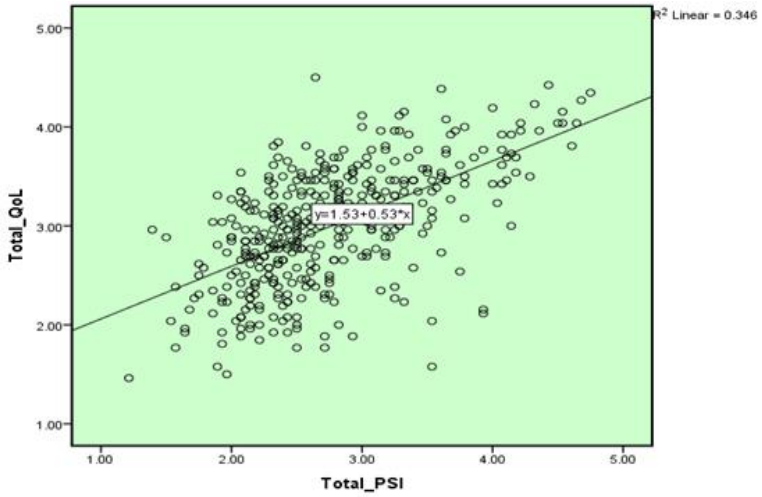

Figure (4.6): Correlation between overall wellbeing and PSI

4.2.5.2 Age of CWDs correlation with overall wellbeing and PSI

The correlation test showed an inversed correlation between age and wellbeing (r = -0.120) at a statistically significant difference in relation to age (P-value = 0.012). The correlation between age and overall wellbeing resulted in a negative correlation which considered to be a weak relationship. In contrast to the correlation between Age and PSI was not statistically significant (P-value=0.520, r=-.032 as shown in Table 4.26.

4.2.5.3 Rest and leisure time correlation with wellbeing and PSI

To examine how time use correlates with QoL and PS, the correlation test was applied and revealed that a positive relationship between rest and leisure time and QoL and PS. These relationships are apparent from the linear ascending relationship shown in Figures,4.7,4.8. Both variables are statistically significant in correlation with rest and leisure time where (P-value =.000) for both and considered moderate in strength as shown in Table 4.26.

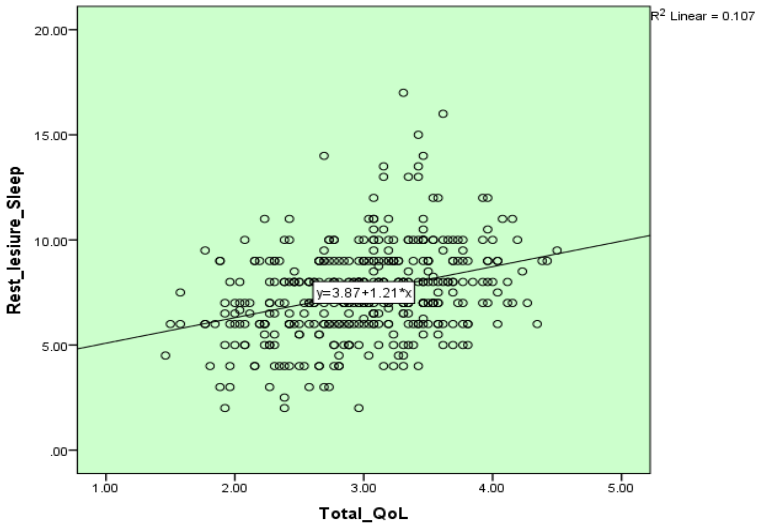

Figure (4.7): Correlation between overall wellbeing and rest, sleep and leisure

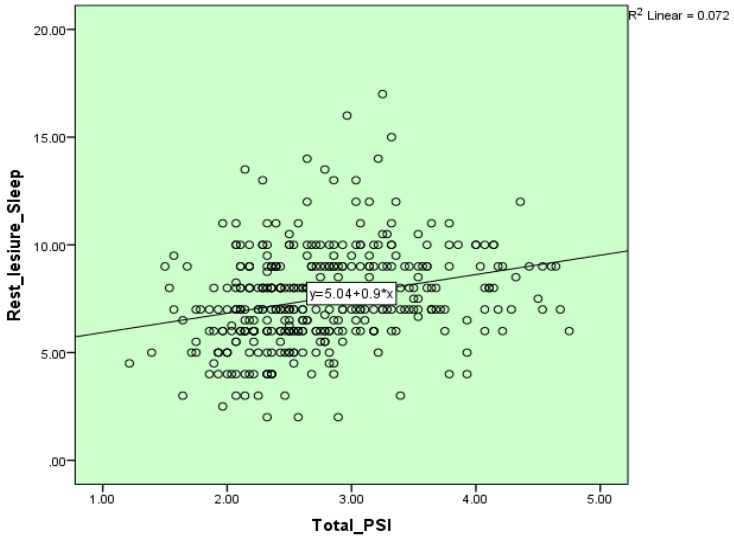

Figure (4.8): Correlation between overall PSI and rest, sleep and leisure

Chapter Five
Conclusion and Recommendations

5.1 Conclusion

The study constructed the conclusion and suggestions to be presented in this chapter based on the findings and results of assessing the study population wellbeing, PSI, disability characteristics of CWDs and faced difficulties, service provision, cultural norms, forgone opportunities, financial and sociocultural burden, and time use.

The tool used to obtain quantitative results, which then have been validated and explained with people in FGDs and KII. Special focus was drawn towards assessing the different aspects of the impact of having CWDs on the life of the caregiver and family. The used tools reflected the range of life aspects thought to constitute or indicate the overall wellbeing in the light of the presence of a disability and to what extent stress due to parenting the CWDs is present and affects the caregiver's life.

The main results indicated that the wellbeing of the caregivers of CWDs elicited moderate LS of QoL. The social relationships domain (satisfaction of relationships, support of friends, sex life) elicited the highest domain and the physical health domain elicited the second highest. In between, psychological and domains environment elicited lower levels of satisfaction. It is noteworthy that the environment was the domain with the least satisfaction.

As well as the study concentrated on the parenting process and the resulted stress due to the parenting of such a child, where the stress was moderate in level and the most domain that indicated more stress was PD domain caregivers where most of the caregivers were feeling that they can't handle things very well besides self-giving up and felt trapped in responsibilities of caregiving. Furthermore, the P-CDI domain and DC domain were equal in levels of stress and better where they were both moderate but with lower figures. Hence, the overall result of PSI was moderate in level.

Clearly, the highest-burden faced in many of the activities related to disability was the financial burden where it was the highest in medical seeking services, education, recreational activities, and others and at the same time, there were difficulties that faced by

caregivers in specific areas such as education, ADL and health services. Regarding education, transportation adaptation was constating the highest-burden followed by an adaptation of educational tools in addition to ADL difficulties where bathing the child was the highest one followed by the dressing. As for health-seeking services, there were many high extent difficulties faced, above all was the medication provision with almost equal extent was the assistive devices and medical disposables provision.

Significantly, some demographic variables had its effect on both wellbeing and PSI. For instance, there was an effect of the locality of living on wellbeing where governorates showed differences in wellbeing. Notably, Rafah was the best of all. Another variable that had an effect was the family type where the extended family showed lower QoL than the nuclear one which is closely connected to the number of HH members that also showed a difference in wellbeing where the lesser the HH members number the better QoL. Also, the average HH income made a difference in wellbeing where the higher the income, the better QoL. Evidently, having another member with a disability in the HH had an effect on wellbeing where the HH that had no other PWD/CWD member showed better QoL.

Undoubtedly, some demographics also affected PSI, which can be seen in the locality the same as wellbeing, where the best PSI also was for Rafah, surprisingly also the refugee status had its effect on PSI where refugees had better PSI. Besides the family type and HH income similar to wellbeing variables which were better in the nuclear family and the higher income.

Although the nature of disability did not show a difference in wellbeing it made a significant effect on PSI, where the behavioral disabilities were the most stressful caregivers among all, followed by learning and cognitive disabilities. Likewise, wellbeing the PSI was affected by the number of HH members whereas lesser members as lesser stress adding to the percentage of expenditures spent on the needs of CWD, where the lesser this percentage the lesser the stress. Above all, there was a linear relationship between wellbeing and PSI where the better the score of any of them the better the other.

Certainly, there were challenges caregivers faced such as forgone opportunities, for instance, the majority of caregivers had difficulties in securing recreational activities and leisure, adding to socialization, attending social events and mixing with other people's challenges. As well as the challenges that members of the family face like siblings where

because of the presence of the CWDs in the family a wide portion had experienced decreased care from parents and lost recreational activities.

Another challenge faced was the cultural norms and people's attitude toward disability, a high portion was found to be supportive especially in the family, however, most of those who were supportive were not helpful and as the circle widens the support decrease and accordingly help. Noticeably, the majority of caregivers feel that the negative attitude from society created psychological problems adding to their worries and their heavy responsibilities. Evidently, there were wellbeing and PSI correlation with time of rest, sleep and leisure as the time increases the better, they were.

It seems likely that many barriers stood in front of caregivers to live a normal life, the most important barrier was the financial barriers, where it was the cause of inability to receive many services such as recreation, health-related services, transportation, and even education, followed by the sociocultural barriers where society attitude made a burden by how they interact with caregivers. Another barrier but with less burden was discrimination especially according to the nature of the disability, which was found to be a barrier for caregivers.

Admitting the heavy burden of disability and, caregiving process, stress, financial burden, social stigma burden, and insufficient services burden on the caregiver, yet this may give the motive to act and try to decrease this heavy load for better caregiver's wellbeing. Effective policies could help to carry with the family the responsibility of the CWDs.

5.2 Recommendations

1. Caregivers mainly mothers carry most of the burden related to disability, therefore there is an urgent need to support them through respite care in order to reduce the burden they shoulder as a result of having a child with a disability.
2. Provide family counseling and family therapy to support the family with CWDs' coping and functional behaviors/relations.
3. CWDs and their families are underserved by service providers, therefore service provision needs to be more disability sensitive e.g. introducing disability-related services in the package of the regular services in health, education, etc.

4. Caregivers need information, education, and counseling that need to be fulfilled through awareness sessions, mass media, social media, and health promotion programs.
5. To facilitate the caring process of CWDs it is important to adapt public places like schools, NGOs, restaurants, community centers, community-based organizations, and recreational places not only to fit physical disability but also other sensory and behavioral ones.
6. More efforts need to be exerted to change service providers and public attitudes about disability to show more positive attitudes, empathy and support PWDs.
7. The low wellbeing status and high paternal stress imply that caregivers need to targeted through psychosocial programs to help them and improve their mental wellbeing.
8. Families with CWDs need to be financially supported to meet the increase in the demand for services due to disability, especially as the CWD advances in age.
9. Disability-related organizations and service providers need to proactively target caregivers of CWDs and enroll them in supportive programs to help them cope with the challenges associated with having a CWD.
10. To break the isolation of caregivers of CWDs, there is a need to establish a forum, an association, entities and support group using peer to peer and woman to woman support groups.
11. To overcome the multi-faceted, multi-sectoral demands associated with having a CWD, it is important to deliver integrated, comprehensive interventions through multi-sectoral cooperation e.g. MOH, MOE, MOSD, Ministry of Transportations, Ministry of Local Governance, and many others.
12. The most disadvantaged caregivers are those with older CWDs, living in poor families, non-refugees, living in extended families, having more than one child with a disability, belonging to large size families and low educational attainments.

5.2.1 Recommendations for new areas of research

1. A larger-scale in-depth qualitative study about wellbeing and parental stress is needed.
2. Conducting specific research studies for each type of disability to in-depth investigate the challenges facing caregivers of each type of disability.

3. Conducting studies involving separately all members of the family including siblings and fathers to have a deep insight and reflections of disability impact.
4. Comparative studies of effective modalities for the social embracing of CWDs and their caregivers.
5. Conducting a specific study about the care economy for disability.
6. Conducting a study about the caregiver mental health and disability outcomes in relation to the CWD such as his/her level of independence, health status, mental health, and school attainment

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Annexes

Annex (1) Study activities time table

Activity	Duration In mon	7	8	9	10	11	12	1	2	3	4	5	6	7	8	9	10
Review literature	2																
Tool development	2																
Tool validation & piloting	2																
Data Collection	3																
Data Entry	2																
Data Analysis	2																
Thesis writing	3																
Dissemination	1																

Annex (2) Sample size calculation by Epi Info.

Population survey or descriptive study
For simple random sampling, leave design effect and clusters equal to 1.

Population size:	14244
Expected frequency:	50 %
Acceptable Margin of Error:	5 %
Design effect:	1.0
Clusters:	1

Confidence Level	Cluster Size	Total Sample
80%	162	162
90%	266	266
95%	374	374
97%	456	456
99%	634	634
99.9%	1006	1006
99.99%	1369	1369

Annex (3) Quantitative study instruments

Questionnaire items (English)

Quality of Life among Caregivers of Children with Disabilities in the Gaza Strip

Caregiver Questionnaire

Code Number (for computer use): _____

Participation Consent

Dear Participant,

I cordially invite you to participate in a research study titled **Quality of Life among Caregivers of Children with Disabilities in the Gaza Strip**. I am currently enrolled in the (Health Management Master program) at Al Quds University in Gaza, I am in the process of writing my Master's Thesis. The purpose of the research is to assess the Quality of life among caregivers of CWDs in order to provide recommendations that ultimately contribute to improving the QoL among caregivers of CWDs and thus improving their physical psychological and wellbeing.

Your participation in this research project is voluntary. You may decline all, or leave any questions you don't wish to answer. There are no known risks to participation beyond those encountered in everyday life. Your responses will remain confidential and anonymous. Data from this research will be kept confidential and reported only as a collective combined total. No one other than the researchers will know your individual answers to this questionnaire. If you agree to participate in this project, please answer the questions as best you can. The interviewed questionnaire should take approximately 20-30 minutes to complete.

If you have any questions about this project, feel free to ask. Thank you for your assistance in this important endeavor.

Sincerely yours,

Mariam A. Mohanna

Identification Details:

1	**Place of living**	**North**	**Gaza**	**Middle**	**Khan Younis**	**Rafah**
2	Address in details:					
3	Telephone:		4. Mobile:		5. Age of respondent:	
6	Completed by:					
	1.Mother		2.Father		3.Brother	
	4.Sister		5.Friend		6.Other-specify:	
7.	Gender of caregiver		1.Male		2. Female	
Quality of life						
	Question	**Very poor**	**Poor**	**Neither poor nor good**	**Good**	**Very good**
QoL1	How would you rate your quality of life?	1	2	3	4	5
QoL2	How satisfied are you with your health?	Very Dissatisfied	Dis-satisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
		1	2	3	4	5
How much you have experienced certain things in the last four weeks.						
		Not at all	A little	A moderate amount	Very much	An extreme amount
QoL3	To what extent do you feel that physical pain prevents you from doing what you need to do?	5	4	3	2	1
QoL4	How much do you need any medical treatment to function in your daily life?	5	4	3	2	1
QoL5	How much do you enjoy life?	1	2	3	4	5
QoL6	To what extent do you feel your life to be meaningful?	1	2	3	4	5
QoL7	How well are you able to concentrate?	1	2	3	4	5
QoL8	How safe do you feel in your daily life?	1	2	3	4	5
QoL9	How healthy is your physical environment?	1	2	3	4	5
How completely you experience or were able to do certain things in the last four weeks.						
QoL10	Do you have enough energy for everyday life?	1	2	3	4	5
QoL11	Are you able to accept your bodily appearance?	1	2	3	4	5
QoL12	Have you enough money to meet your needs?	1	2	3	4	5
QoL13	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
QoL14	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
QoL15	How well are you able to get around?	1	2	3	4	5
		Very Dissatisfied	**Dis-satisfied**	**Neither satisfied nor dissatisfied**	**Satisfied**	**Very satisfied**
QoL16	How satisfied are you with your sleep?	1	2	3	4	5
QoL17	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
QoL18	How satisfied are you with your capacity for work?	1	2	3	4	5
QoL19	How satisfied are you with yourself?	1	2	3	4	5
QoL20	How satisfied are you with your personal relationships?	1	2	3	4	5
QoL21	How satisfied are you with your sex life?	1	2	3	4	5
QoL22	How satisfied are you with the support you get from your friends?	1	2	3	4	5
QoL23	How satisfied are you with the conditions of your living place?	1	2	3	4	5
QoL24	How satisfied are you with your access to health services?	1	2	3	4	5
QoL25	How satisfied are you with your transport?	1	2	3	4	5
		Never	**Seldom**	**Quite often**	**Very often**	**Always**
QoL26	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	5	4	3	2	1
Parental Stress index						
	Question	**Strongly disagree**	**Disagree**	**Neutral**	**agree**	**Strongly agree**
S1	I often have the feeling that I cannot handle things very well	5	4	3	2	1
S 2	I find myself giving up more of my life to meet the child's needs than I ever expected	5	4	3	2	1
S 3	I feel trapped by my responsibilities as a caregiver.	5	4	3	2	1
S 4	Since having the child, I have been unable to try new and different things	5	4	3	2	1

S5	Since having the child, I feel that I am almost never able to do things that I like to do	5	4	3	2	1
S 6.	I am unhappy with the last purchase of clothing I made for myself	5	4	3	2	1
S 7.	There are quite a few things that bother me about my life	5	4	3	2	1
S 8.	Having a child has caused more problems than I expected in my relationship with my spouse/family.	5	4	3	2	1
S 9.	I feel alone and without friends When I go to a party, I usually expect not to enjoy myself	5	4	3	2	1
S 10	I am not as interested in people as I used to be	5	4	3	2	1
S 11	I don't enjoy things as I used to	5	4	3	2	1
S 12	The child rarely does things for me that make me feel good	5	4	3	2	1
S 13	Most times I feel that the child likes me and wants to be close to me	5	4	3	2	1
S 14	The child smiles at me much less than I expected	5	4	3	2	1
S 15	When I do things for the child, I get the feeling that my efforts are not appreciated very much	5	4	3	2	1
S 16	When playing, the child doesn't often giggle or laugh	5	4	3	2	1
S 17	The child doesn't seem to learn as much as most children	5	4	3	2	1
S 18	The child is not able to do as much as I expected	5	4	3	2	1
S 19	It takes a long time and it is really hard for the child to get used to new things	5	4	3	2	1
S 20	I expected to have closer and warmer feelings for the child than I do and this bothers me	5	4	3	2	1
S 21	The child generally wakes up in a bad mood	5	4	3	2	1

S 22	I feel that the child is very moody and easily upset	5	4	3	2	1
S 23	The child does a few things that bother me a great deal	5	4	3	2	1
S 24	The child reacts very strongly when something happens that my child doesn't like	5	4	3	2	1
S 25	Sleeping and eating schedule was much harder to establish than I expected	5	4	3	2	1
S 26	The child turned out to be more of a problem than I expected	5	4	3	2	1
S 27	The child makes more demands on me than most children	5	4	3	2	1
S 28	The child seems to cry more often than most children	5	4	3	2	1
S 29	Think carefully and count the number of things which your child does that bothers you:					
Questions belong to the HH of the CWD **CWD Caregiver individual characteristics**						
D1	Current Marital status?					
	1. Never Married			3.Divorced		
	2. Currently married			4.Widowed		
D2	Refugee status		1.Refugee		2.Nonrefugee	
D3	Who do you live with?					
	1.Alone		3.Extended family			
	2.Nuclear family		4.Other-specify...			
D5	Number of children under 18:			D4. Number of household members		
D6	Having other HH members with disabilities?		1.Yes		2.No Go to D7	
D7	If yes in the previous question		2.Number of adults with disabilities……		1.Number of CWD……	
D8	Caregiver 's educational level attained		1.Illiterate		5.Diploma	
			2.Elementary		6.Bachelor	
			3.Preparatory		7.Postgraduate/higher education	
			4.Secondary			
D9.	Mother's employment status		1. not working		4.Working intermittent	
			2.Working full time		5.Retired	
			3.Working part-time		6.Others:……	
D10.	Father's educational level attained		1.Illiterate		5.Diploma	
			2.Elementary		6.Bachelor	
			3.Preparatory		7.Postgraduate/higher education	
			4.Secondary			
D11.	Father's Employment status(current)		1.Not working		4. Working intermittent	
			2.Working full time		5.Retired	
			3.Working part time		6.Others:…….	
D12.	Average HH monthly income from all sources		1. …… (NIS)		3.Refused to answer	
			2.Don't Know			

D13.	What is the main source of income for the caregiver HH?			
	1.Employment of the caregiver	6.Spouse 's employment		
	2.Revenues from family assets	7.Pension from family member		
	3.Assistance from MOSD	8.Other families -not relatives		
	4.Assistance from UNRWA	9.Employment from siblings		
	5.Charitable local NGOs-indicate name:	10.Other (please specify)		
D14.	Average monthly expenditure:			
D15.	How much % of your expenditures spent on the needs related to the CWD			
Child individual characteristics				
C1.	Record sex of CWD:	1.Female	2. Male	C2. Age in years:
C3.	What is the highest level of education attained by CWD?			
	Grade	Standard education	Special education	
	1.Kinder garden			
	2.Primary			
	3.Preparatory			
	4.Secondary			
	5.Vocational training			
	6.Others specify:			
	7.Not applicable			
C4.	What is the nature of disability? (tick all that apply)			
	1.Visual/seeing	4.Hearing/speech		
	2.Physical/mobility	5.Learning/cognitive		
	3.Behavioral	6.Multiple (please specify)		
C5.	At what age have the child acquire disability? 1.At birth:…… 2.In years……..			
C6.	What type of therapy/medical care have been provided to CWD this year? (tick all that apply)			
	1.Speech/language therapy	8.Audiology services		
	2.Occupational therapy	9.Orthopedic/prosthetic therapy		
	3.Physiotherapy	10.Psychosocial/mental health		
	4.Provision of disposables such as diapers, dressings	11.Assistive devices		
	5.Medications	12.Others specify……		
	6.Specialized medical care	13.Not applicable		
	7.Medical follow up			
C7.	Does the medical therapy/care needed for your CWD constitute a burden on HH or on you personally?	1.Yes	2.No	
	If yes specify the burden:			
	1.Financial	5.Discrimination		
	2.physical	6.Stigma		
	3.Forgone Opportunities	7.quality of service		
	4.Social burden	8.Other please specify:		
C8.	Who helps you in the medical care? Please specify:			
C9.	In what form:……..			
C10.	Does medical care needed for the CWD prevent you from doing the things you want to do?			
	1.Yes	2.No		
C11.	If yes, what things does medical care prevents you from doing?			
	1.House work	4.caring for other siblings	7.caring for other HH members	
	2.Your work	5.recrational and leisure activities	8.rest	
	3.education	6.socialization	9.Rest and sleep	
	10.others, please specify:			

C12.	Due to disability, do you have difficulties related to the child education?				
		No burden	Some burden	Huge burden	Not applicable
	1.Transportation adaptation				
	2.Classroom adaptation				
	3.Toilets adaptation				
	4.Educational tools adaptation				
	5.School entrance and exits				
	6.Roads leading to school				
	7.School playfield				
	8.Resource centers such as computer lap				
	9.Finding a school that accepts/enrolls CWDs				
	10.Finding a school that can deal with CWDs conditions and needs				
	11.Attitudes of school teachers				
	12.Attitudes of peers at school				
	13. Others specify…….				
C13.	Do you receive help in the education of your CWD?	1.Yes		2.No	
C14.	If Yes in what form?				
C15.	Who helps?				
C16.	Does CWD education constitute a burden on you?	1.Yes		2.No	
C17.	If yes specify the burden:				
	1.Financial	5.Discrimination			
	2.physical	6.Stigma			
	3.Forgone Opportunities	7.quality of service			
	4.Social burden	8.Other please specify:			
C18.	Due to the disability, does the CWD have difficulties in the following activities of the daily living and constitute a burden on you?				
		No burden	Some burden	Huge burden	Not applicable
	1.Dressing by him/herself				
	2.Feeding by him/herself				
	3.Getting in and out of bed				
	4.Bathing/washing				
	5.Moving about in the home				
	6.Moving about outdoors				
	7.Getting in and out of a motor vehicle (car, bus.)				
C19.	Do you receive help in activities of daily living of your CWD?	1.Yes		2.No	
C20.	If yes, in what form?				
C21.	Who Helps?				
Service Provision:					
	What services currently do you receive and are they adequate? do they help?				
SP1.	Health services	1.Not received 2. Received	1.Not adequate 2.Adequate	1.Not Helpful 2.Helpful	1.I face a burden 2. I didn't face burden
SP2.	Educational services	1.Not received 2. Received	1.Not adequate 2.Adequate	1.Not Helpful 2.Helpful	1.I face a burden 2. I didn't face burden
SP3.	Financial assistance	1.Not received 2. Received	1.Not adequate 2.Adequate	1.Not Helpful 2.Helpful	1.I face a burden 2. I didn't face burden
SP4.	Outreach services	1.Not received 2. Received	1.Not adequate 2.Adequate	1.Not Helpful 2.Helpful	1.I face a burden 2. I didn't face burden

SP5.	Psychosocial services	1.Not received 2. Received	1.Not adequate 2.Adequate	1.Not Helpful 2.Helpful	1.I face a burden 2. I didn't face burden
SP6.	I don't receive any service	1.Yes		2.No	
SP7.	Do you need services that are not provided?	1.Yes		2.No	
SP8.	If yes, please specify……				
SP9.	Due to disability of your CWD, Do you have difficulties in securing the following related to health services and constitute a burden on you?				

	No burden	Some burden	Huge burden	Not applicable
1.Reaching the health services				
2.Availability of the needed services				
3.Support of staff				
4.Respect from staff				
5.Information about health services				
6.Medications				
7.Counselling services				
8.Medical disposals				
9.Assistive devices				
10.Others, please specify				

SP10.	Do you have any health problems attributed to caregiving activities?	1.Yes	2.No
SP11.	If yes, do you receive medical care for your health problem?	1.Yes	2.No

Cultural Norms

N1.	Are the following people's attitudes to the CWD with regard to his/her disability supportive or disabling?	1.Supporting 2. Neither supporting nor disabling 3. Disabling 4. Not applicable	Helps and reduces the burden 1-yes 2-somewhat 3-no
	1.Partner		
	2.Your Mother		
	3.Your Father		
	4.CWD Sisters		
	5.CWD Brothers		
	6.Other family members like aunts		
	7.Mother in low		
	8.Father in low		
	9.Peers at school/preschool		
	10.Neighbors		
	11.Teachers		
	12.Taxi drivers		
	13.Health providers		
	14.Doctors		
	15.Nurses		
	16.Salesman at shops		
	17.People at mosques/church		
	18.People at recreational places like restaurants-staff/customers		

Forgone opportunities					
FO1.	Because of the disability of child did you experience any of the listed below (tick all that apply)	Very much	Somewhat	No	Not applicable
1.	Difficulties mixing with other people				
2.	Difficulties in finding a job				
3.	Difficulties in keeping a job				
4.	Difficulties in enrolling in education				
5.	Difficulties in securing recreational activities				
6.	Difficulties to have leisure activities such as: watching television; reading; relaxing or thinking; playing computer, board, or card games; using a computer or the Internet for personal interest; playing or listening to music; and other activities, such as attending arts, cultural, and entertainment events.				
7.	Forgone opportunities to socialize with others				
8.	Difficulties in hosting people				
9.	Difficulties in attending social events				
FO2.	Does any one of the siblings experience any of the following forgone opportunities				
1.	Decreased Care from father/mother				
2.	Lost education				
3.	Lost recreational activities				
4.	Lost socialization				
5.	Lost needs				
Financial burden					
FB1.	What services or care would like to receive, but unable to receive it? Tick all that apply				
	Service	1.yes 2.No	Reasons for not receiving the service 1. lack or unavailability of the service 2. poor quality of services 3. physical accessibility barriers 4. not knowing where to go 5. lack of adequate number of organizations 6. too long waiting lists 7. social barriers 8. not medically insured financial difficulties		
	1.None				
	2.Speech /language therapy Audiology services				
	3.Rehabilitation services				
	4.Provision of disposables				

	5.Social assistance					
	6.Health services/medical services					
	7.Psychological /mental health					
	8.Education services					
	9.Recreation					
	10.Transportation					
	11.Assistive devices					
	12. Others specify…….					
Psychosocial burden						
SC1.	Do services providers and or policymakers discriminate among CWD in reference to	1. Yes 2. No				
	Reasons behind disability					
	Age of CWD					
	Gender of CWD					
	Socioeconomic status					
SC2.	I find difficulty in dealing with my CWD	Strongly agree	agree	neutral	disagree	Strongly disagree
SC3.	My child's disability has an effect on not forming a new relationship					
SC4.	My child disability makes me feel alone and isolated					
SC5.	I feel worried about the future					
SC6.	I feel ashamed because of my child disability					
SC7	The negative attitude of society creates psychological problems for me					
SC8	My ambitions were broken because of my child disability					
SC9	Disability exhausts us financially					
SC10.	Did you receive training or counseling about how to deal with CWDS?	1.Yes		2.No		
SC11.	Does any organization or service provider provide you with any of the following?	Ever, since acquiring the disability 1.Yes 2.No		In the past year 1.Yes 2.No		
	1.Training or counseling on how to deal with CWDs					
	2.Counseling on the basic care					
	3.Dealing with the health aspect of the care					
	4.Dealing with the assistive devices					
	5.Dealing with the education aspect					
	6.Residential care					
	7.Home based care					

Time use **TU: How much time do you spend in the following activities during 24 hours?**			
No	**Activity**	**Mother/caregiver**	
1	Sleeping		
2	Eating and drinking		
3	Housework		
4	Food preparation and cleanup		
5	Purchasing goods and services		
6	Professional and personal care services		
7	Caring for and helping household members		
8	Caring for and helping household children		
9	Caring for and helping non-household members		
10	Caring for and helping non-household adults		
11	Working		
12	Educational activities		
13	Attending class		
14	Homework and research		
15	Religious and spiritual activities		
16	Leisure and sports		
17	Socializing and communicating		
18	Watching television		
19	Participating in sports, exercise, and recreation		
20	Telephone calls, mail, and e-mail		
21	Other activities, not elsewhere classified		
Time adults spent caring for household children			
No	**TUC: Childcare activities for (CWD)**	**Average time per Day**	
		Mother	**Father**
1	Children under age 18, total…….		
2	Caring for household children as a primary activity		
3	Physical care		
4	Education-related activities		
5	Reading to/with children		
6	Talking to/with children		
7	Playing/doing hobbies with children		
8	Looking after children		
9	Attending children's events		
10	Other childcare activities		
	TUS: Childcare activities (siblings)	**Average time per Day**	
		Mother	**Father**
1	Children under age 18, total…….		
2	Caring for household children as a primary activity		
3	Physical care		

4	Education-related activities		
5	Reading to/with children		
6	Talking to/with children		
7	Playing/doing hobbies with children		
8	Looking after children		
9	Attending children's events		
10	Other childcare activities		

ES1: Please mentions the Services you wish to have at home for CWDs

_____
_____

ES2: Things you wish organizations serving CWDs can do to reduce the burden on your shoulders

_____
_____

ES3: Others comments

_____
_____

Thank you

Questionnaire items (Arabic)

نوعية الحياة بين مقدمي الرعاية للأطفال ذوي الإعاقة في قطاع غزة

استبيان مقدمي الرعاية

رقم الكود(لاستخدام الكمبيوتر):

موافقة على المشاركة:

عزيزي المشترك

أتشرف بدعوتكم للمشاركة في دراسة بحثية بعنوان"نوعية الحياة بين مقدمي الرعاية للأطفال ذوي الإعاقة في قطاع غزة"وذلك لاعداد رسالة الماجستير في الإدارة الصحية.إن هدف البحث هو تقييم جودة الحياة لدى مقدمي الرعاية للأطفال ذوي الإعاقة لتقديم التوصيات التي ستسهم في تحسين جودة حياتهم جسديا ونفسيا.

إن مشاركتك في هذا البحث طوعية حيث يمكنك أن ترفض المشاركة أو ترفض الاجابة على أي سؤال.كما لا يوجد أي خطر يترتب على مشاركتك .ستكون المعلومات التي تشارك بها سرية وبلا هوية وستعرض بشكل جماعي ولن يعرف بها الا الباحثة.

في حال موافقتك على الاشتراك ،يرجى التكرم بالإجابة على أسئلة الاستبانه والتى قد تحتاج تقريبا من 20-30 دقيقة .

إذا كانت لديك أي أسئلة تتعلق بالبحث لا تتردد في السؤال.

ولكم جزيل الشكر والعرفان لمساهمتكم الفاعلة .

الباحثة: مريم أكرم مهنا

المعلومات الشخصية:

1	مكان السكن:	الشمال	غزة	الوسطى	خانيونس	رفح
2	العنوان بالتفصيل:					
3	رقم التليفون الارضي:		4.الجوال:		5 العمر:	
6	تمت التعئبة بواسطة:					
	1.الام	2.الاب		3.الاخ		
	4.الاخت	5.الاصدقاء		6.اخرون – حدد:		
7	جنس مقدم الرعاية	1. ذكر		2. انثى		

مقياس جودة الحياة

		سيئة جدا	سيئة إلى حد ما	لا سيء ولا جيد	جيدة إلى حدما	جيد جدا
QoL1.	ماهو تقديرك لنوعية الحياة ؟	1	2	3	4	5
QoL 2.	ماهو مدى رضاك عن صحتك؟	غير راض أبدا	غير راضي نوعاما	لا راضي ولا غير راضي	راضي نوعا ما	راضي جدا
		ليس دائما	بدرجة قليلة	بدرجة متوسطة	كثيرا	بدرجة بالغة
QoL 3.	من رأيك إلي أي مدي يمكن أن يؤدي مرضك إلي عجزك عن القيام بالعمل ؟	5	4	3	2	1
QoL 4.	هل تحتاج إلى الرعاية الطبية لتمارس عملك اليومي؟	5	4	3	2	1
QoL 5.	ما مدى استمتاعك بالحياة؟	1	2	3	4	5
QoL 6.	ما مدي شعورك بوجود معني لحياتك ؟	1	2	3	4	5
QoL 7.	إلي أي مدى يمكنك تركيز عقلك ببساطة ؟	1	2	3	4	5
QoL 8.	ما مدى شعورك بالأمن في الحياة؟	1	2	3	4	5
QoL 9.	ما مدي الاهتمام الصحي في بيئتك الطبيعية ؟	1	2	3	4	5
QoL 10.	هل لديك الكفاية و الفاعلية الكافية للقيام بواجبات الحياة إليومية ؟	1	2	3	4	5
QoL 11.	هل أنت متقبل لبنائك الجسدي ؟	سيئة جدا	سيئة إلى حد ما	لا سيء ولا جيد	جيدة إلى حدما	جيد جدا
QoL 12.	هل أنت كفء لإشباع احتياجاتك ؟	سيئة جدا	سيئة إلى حد ما	لا سيء ولا جيد	جيدة إلى حدما	جيد جدا
QoL 13.	ما مدى توفر المعلومات اللازمة والتي تحتاجها في حياتك اليومية؟	ليس دائما	بدرجة قليلة	بدرجة متوسطة	كثيرا	بدرجة بالغة
QoL 14.	لاي مدى لديك فرصة للراحة والاسترخاء؟	ليس دائما	بدرجة قليلة	بدرجة متوسطة	كثيرا	بدرجة بالغة
QoL 15.	كم أنت قادر علي التنقل هنا وهناك ؟	ليس دائما	بدرجة قليلة	بدرجة متوسطة	كثيرا	بدرجة بالغة
		غير راض أبدا	غير راضي نوعاما	لا راضي ولا غير راضي	راضي نوعا ما	راضي جدا
QoL 16.	إلى أي مدى أنت راضٍ عن نومك؟	1	2	3	4	5

QoL 17.	ما مدى رضاك عن أدائك لواجباتك اليومية؟	1	2	3	4	5
QoL 18.	ما مدى رضاك عن قدرتك على العمل؟	1	2	3	4	5
QoL 19.	ما مدى رضاك عن نفسك؟	1	2	3	4	5
QoL 20.	ما مدى رضاك عن علاقاتك الشخصية؟	1	2	3	4	5
QoL 21.	ما مدى رضاك عن حياتك الجنسية؟	1	2	3	4	5
QoL 22.	كم أنت راضياً عن المساندة الاجتماعية التي يقدمها لك أصدقائك ؟	1	2	3	4	5
QoL 23.	ما مدي رضاك عن سكنك أو المكان الذي تعيش فيه ؟	1	2	3	4	5
QoL 24.	ما هو مدى رضاك عن الخدمات الصحية التي يقدمها المجتمع ؟	1	2	3	4	5
QoL 25.	ما هو مدي رضاك عن مزاجك ورحلاتك ؟	1	2	3	4	5
QoL 26.	كم مرة شعرت فيها بالحزن ، الاكتئاب ، والقلق ؟	ليس دائما	بدرجة قليلة	بدرجة متوسطة	كثيرا	بدرجة بالغة
أسئلة تتعلق بأسرة الطفل ذي الاعاقة **مؤشر الضغط النفسي لدى مقدم الرعاية**						
		أرفض بشدة	أرفض	محايد	موافق	موافق بشدة
S1.	أشعر أحيانا أنني لا استطيع التعامل مع الاشياء بشكل جيد					
S 2.	أجد نفسي أضحي بحياتي لتلبية احتياجات الطفل أكثر مما توقعت					
S 3.	أشعر أن مسئولياتي كمقدم رعاية تقيدني					
S 4.	منذ ولادة الطفل اشعر بأنني غير قادر على تجربة أشياء جديدة ومختلفة					
S 5.	منذ ولادة الطفل أشعر أنني غير قادر على ممارسة الامور التي أحبها					
S 6.	أنا غير راض عن اخر مرة اشتريت فيها ملابس لنفسي					
S 7.	هناك عدد لا بأس به من الاشياء التي تزعجني في حياتي.					
		أرفض بشدة	أرفض	محايد	موافق	موافق بشدة
S 8.	تسبب إنجاب طفل بمشاكل أكثر مما توقعت في علاقتي مع زوجي /زوجتي/افراد الاسرة					

S 9.	أشعر بالوحدة ومن دون أصدقاء عندما أذهب إلى مناسبة أتوقع عادة ألا أستمتع بنفسي					
S 10.	أنا لا اهتم بالناس كما كنت في السابق.					
S 11.	أنا لا استمتع بالاشياء كما كنت في السابق					
S 12.	نادراً ما يقوم الطفل بأشياء تجعلني أشعر أنني بحالة جيدة					
S 13.	غالبا أشعر بأن الطفل يحبني ويريد أن يبقى بجانبي					
S 14.	الطفل يبتسم لي أقل بكثير مما كنت أتوقع					
S 15.	عندما أفعل أشياء للطفل ، أشعر بأن جهودي لا تحظى بتقدير كبير					
S 16.	لايضحك الطفل كثيرا عند اللعب					
S 17.	يبدو أن الطفل لا يتعلم بقدر باقي الاطفال					
S 18.	الطفل غير قادر على القيام ببعض الاشياء بالقدر الذي كنت أتوقعه					
S 19.	يستغرق الطفل وقتا طويلا ومن الصعب عليه التعود على أشياء جديدة					
S 20.	كنت أتوقع أن تكون مشاعري أقرب وأكثر دفئا للطفل وذلك يزعجني					
S 21.	بشكل عام يستيقظ الطفل بمزاج سيء					
S 22.	أشعر أن الطفل مزاجي جدا ويغضب بسهولة					
S 23.	يقوم الطفل ببعض الاشياء التي تزعجني جدا					
S 24.	عند حصول ما لا يعجب الطفل يعطي ردة فعل قوية جدا					
S 25.	جدول مواعيد النوم والأكل أصعب بكثير مما توقعت					
S 26.	تبين لي أن الطفل يسبب مشكلة أكثر مما توقعت					
S 27.	يطالبني الطفل بكثير من المطالب أكثر من معظم الأطفال					
S 28.	يبدو أن الطفل يبكي أكثر من معظم الأطفال					
S 29.	فكر جيداً واحسب عدد الأشياء التي يفعلها الطفل والتي تزعجك:					

أسئلة تتعلق بأسرة الطفل ذي الاعاقة **الخصائص الفردية لمقدم الرعاية للطفل ذي الاعاقة**			
D1.	الحالة الاجتماعية الحالية		
	1.غير متزوج		3.مطلق
	2.متزوج		4.أرمل
D2.	1.لاجيء		2.مواطن
D3.	مع من تسكن؟		
	1.بمفردي		3.أسرة ممتدة
	2.أسرة نووية		4.أخرى/ يرجى التحديد
D4.	عدد الأطفال أقل من 18 سنة:		D5. عدد سكان المنزل:
D6.	هل يوجد في المنزل أشخاص ذوي إعاقة اخرون ؟	1.نعم	2.لا اذهب إلى سؤال 8
D7.	إذا كانت الاجابة نعم في السؤال السابق	1.عدد الاطفال ذوي الاعاقة:	2.عدد البالغين ذوي الاعاقة:
D8.	المستوى التعليمي لدى مقدم الرعاية	1.أمي	5.دبلوم
		2.تعليم أساسي	6.بكالوريوس
		3.إعدادي	7.دراسات عليا
		4.ثانوي	
D9.	الوضع الوظيفي للأم	1.لا تعمل	4.تعمل بشكل متقطع
		2.تعمل بدوام كامل	5.متقاعدة
		3.تعمل بدوام جزئي	6.غيرذلك:
D10.	المستوى التعليمي لدى الأب	1.أمي	5.دبلوم
		2.تعليم أساسي	6.بكالوريوس
		3.إعدادي	7.دراسات عليا
		4.ثانوي	
D11.	الوضع الوظيفي للأب	1.لا يعمل	4.تعمل بشكل متقطع
		2.يعمل بدوام كامل	5.متقاعد
		3.يعمل بدوام جزئي	6.غيرذلك:
D12.	متوسط الدخل الشهري على المنزل من جميع المصادر	1 .....شيكل	3. أرفض الاجابة
		2.لا أعرف	
D13.	ما هو مصدر الدخل الرئيسي في بيت مقدم الرعاية؟		
	1.عمل مقدم الرعاية		6.عمل الزوج/الزوجة
	2.ايرادات من ممتلكات العائلة		7.راتب تقاعد أحد أفراد العائلة
	3.مساعدات وزارة التنمية الاجتماعية		8.من عائلات أخرى- غير أقارب
	4.مساعدات من الأنروا		9.عمل الاخوة
	5.موسسات غير حكومية خيرية/اذكر اسمها:		10.غير ذلك (يرجى التحديد):
D14.	متوسط النفقات الشهرية:		
D15.	كم نسبة النفقات التي تنفق على الاحتياجات الخاصة بالطفل ذي الاعاقة :		
الخصائص الفردية للطقل ذي الاعاقة			
C1.	جنس الطفل	1 أنثى	2 ذكر
C2.	العمر بالسنوات:		
C3.	ما هي أعلى درجة علمية حصل عليها الطقل ذي الاعاقة؟		
	المرحلة	تعليم نظامي	تعليم خاص
	1.روضة		
	2.أساسي		
	3.إعدادي		
	4.ثانوي		
	5.تدريب مهني		
	6.غير ذلك/حدد:		
	7.لا ينطبق		

C4.	ما هي طبيعة الإعاقة؟ (يرجى تحديد كل ما ينطبق على الطفل)						
	1.بصري			4.سمعي/نطق			
	2.جسدي/حركي			5.تعليمي/عقلي			
	3.سلوكي			6.متعدد (لطفا حدد)			
C5.	في أي عمر حدثت الاعاقة للطفل: 1.منذ الولادة:..... 2.منذ كم سنة:.....						
C6.	ما نوع الرعاية الطبية التي تلقاها الطفل ذي الاعاقة هذه السنة؟ (يرجى تحديد كل ما ينطبق)						
	1.علاج النطق			8.خدمات سمعية			
	2.علاج وظيفي			9.أجهزة تعويضية/ أطراف صناعية			
	3.علاج طبيعي			10.صحة نفسية اجتماعية			
	4.توفير مستلزمات مثل : الحفاظات والغيارات			11.أجهزة مساعدة			
	5.أدوية			12.غير ذلك / يرجى التحديد:.....			
	6.عناية طبية متخصصة			13.لا ينطبق			
	7.متابعة طبية						
C7.	هل تشكل الرعاية الطبية التي يحتاجها الطفل ذي الاعاقة عبئا على المنزل أو عليك شخصيا؟		1. نعم		2.لا		
	إذا كانت الاجابة نعم حدد طبيعة العبء:						
	1.مالي			5.تمييز اجتماعي			
	2.جسدي			6.وصمة اجتماعية			
	3.فرص ضائعة			7.جودة الخدمة			
	4.اجتماعي			8.غير ذلك / يرجى التحديد:			
C8.	من يساعدك في تقديم الرعاية الطبية ؟ يرجى التحديد:						
C9.	شكل المساعدة:						
C10.	هل تمنعك الرعاية الطبية للطفل من القيام بالاشياء التي تود القيام بها؟						
	1 .نعم			2 . لا			
C11.	إذا كانت الإجابة نعم، ما هي الأشياء التي تمنعك الرعاية الطبية من القيام بها؟						
	1 أعمال المنزل		4 الاهتمام بالاخوة الاخرين		7 الاهتمام بأفراد المنزل الاخرين		
	2 عملك		5 الانشطة الترفيهية		8 الراحة		
	3 التعليم		6 النشاطات الاجتماعية		9 النوم		
	10 غير ذلك / يرجى التحديد						
C12.	بسبب الاعاقة، هل تواجه صعوبات تتعلق بتعليم الطفل؟						
		لا عبء	بعض العبء	عبء كبير	لا استطيع	لا ينطبق	
	1.مواءمة المواصلات						
	2.مواءمة الفصل الذي يدرس فيه الطفل						
	3.مواءمة الحمامات						
	4.مواءمة الادوات التعليمية						
	5.مدخل ومخرج المدرسة						
	6.الطرق المؤدية للمدرسة						
	7.ملعب المدرسة						
	8.مراكز الموارد مثل مختبر الكمبيوتر						
	9.ايجاد مدرسة تقبل التحاق الطفل بها						
	10.ايجاد مدرسة تستطيع التعامل مع احتياجات وحالات الاطفال ذوي الاعاقة						
	11.مواقف المعلمين						
	12.مواقف الطلاب في المدرسة						
	13.غير ذلك / يرجى التحديد						
C13.	هل تتلقى المساعدة في تعليم طفلك ذي الاعاقة؟	1 نعم			2 لا		
C14.	إذا كانت الاجابة نعم ، ما شكل المساعدة؟						
C15.	من يساعدك في تعليم طفلك ذي الاعاقة؟						
C16.	هل يشكل تعليم طفلك عبئا عليك؟	1 نعم			2 لا		
	إذا كانت الاجابة نعم لطفا حدد طبيعة العبء:						

C17.	1 مالي			5 تمييز اجتماعي		
	2 جسدي			6 وصمة اجتماعية		
	3 فرص ضائعة			7 جودة الخدمة		
	4 عبء اجتماعي			8 غير ذلك / يرجى التحديد		
C18.	بسبب الاعاقة،هل يواجه طفلك صعوبات في أداء وظائف الحياة اليومية والتي تشكل عبئا عليك؟					
		لا عبء	بعض العبء	عبئا كبيرا	لا استطيع	لا ينطبق
	1.يرتدي ملابسه بنفسه					
	2.يأكل بنفسه					
	3.الدخول والخروج من السرير					
	4.الاستحمام					
	5.التحرك داخل المنزل					
	6.التحرك خارج المنزل					
	7.الركوب والنزول من مركبة (سيارة ،باص..)					
C19.	هل تتلقى المساعدة في نشاطات الحياة اليومية لطفلك؟		1 نعم		2 لا	
C20.	إذا كانت الاجابة نعم، ما شكل المساعدة؟					
C21.	من الذي يساعدك؟					
تقديم الخدمات						
	ما هي الخدمات التي تتلقاها حالياً وهل هي كافية؟ هل يساعدون؟					
SP1.	خدمات طبية	1 أتلقى 2 لا أتلقى	1 غير كافية 2 كافية	1 مفيدة 2 غير مفيدة	1 أواجه عبء 2 لا أواجه عبء	
SP2.	خدمات تعليمية	1 أتلقى 2 لا أتلقى	1 غير كافية 2 كافية	1 مفيدة 2 غير مفيدة	1 أواجه عبء 2 لا أواجه عبء	
SP3.	مساعدات مالية	1 أتلقى 2 لا أتلقى	1 غير كافية 2 كافية	1 مفيدة 2 غير مفيدة	1 أواجه عبء 2 لا أواجه عبء	
SP4.	خدمات تصل إلى المنزل	1 أتلقى 2 لا أتلقى	1 غير كافية 2 كافية	1 مفيدة 2 غير مفيدة	1 أواجه عبء 2 لا أواجه عبء	
SP5.	خدمات نفسية اجتماعية	1 أتلقى 2 لا أتلقى	1 غير كافية 2 كافية	1 مفيدة 2 غير مفيدة	1 أواجه عبء 2 لا أواجه عبء	
SP6.	لا اتلقى خدمات	1 نعم		2 لا		
SP7.	هل تحتاج لخدمات أخرى غير مقدمة؟	1 نعم		2 لا		
SP8.	إذا كانت الاجابة نعم، يرجى التحديد:.....					
SP9.	بسبب الاعاقة ،هل تواجه صعوبات في تأمين الخدمات التالية والتي تتعلق بالخدمات الصحية وتشكل عليك عبئا؟					
		لا عبء	بعض العبء	عبئا كبيرا	لا استطيع	لا ينطبق
.1	الوصول للخدمات الصحية					
.2	توفر الخدمات الصحة					
.3	دعم الفريق /الموظفين					
.4	الاحترام من الموظفين					
.5	معلومات عن الخدمات الصحية					
.6	أدوية					
.7	خدمات استشارية					
.8	مستلزمات طبية					
.9	أجهزة مساعدة					
.10	غير ذلك/ لطفا حدد					
SP10.	هل لديك مشاكل صحية ناتجة عن تقديم الرعاية؟	1 نعم يرجى التحديد.....		2 لا		
SP11.	اذا كانت الاجابة نعم،هل تتلقى العلاج لمشكلتك الصحية؟	1 نعم		2 لا لماذا؟.....		

المعتقدات الثقافية			
N1.	هل مواقف الاشخاص التالية من الطفل ذي الاعاقة فيما يتعلق بإعاقته تعتبر داعمة أو عائقة؟	1 داعمة 2 عائقة 3 غير داعم وغير عائق 4 لا ينطبق	يساعد ويقلل العبء 1 نعم 2 بعض الشيء 3 لا
	1.الزوج/الزوجة		
	2.والدتك		
	3.والدك		
	4.أخوات الطفل ذي الاعاقة		
	5.إخوة الطفل ذي الاعاقة		
	6.أفراد اخرين من العائلة مثل العمات أو الخالات		
	7.الحماة		
	8.الحمى		
	9.الزملاء في المدرسة		
	10.الجيران		
	11.المعلمين		
	12.السائقين		
	13.مقدمي الرعاية الصحية		
	14.الاطباء		
	15الممرضين		
	16.الباعة في المتاجر		
	17.الناس في المسجد او الكنيسة		
	18.الناس في الاماكن الترفيهيه مثل المطاعم /الزبائن		

فرص ضائعة					
FO1.	بسبب إعاقة الطفل ،هل واجهت أي من التالي؟ حدد كل ما ينطبق	كثيرا	بعض الشيء	لا	لا ينطبق
1.	صعوبات في الاختلاط بين الناس				
2.	صعوبات في ايجاد وظيفة				
3.	صعوبات في الحفاظ على وظيفة				
4.	صعوبات في الالتحاق بالتعليم				
5.	صعوبات في تأمين الانشطة الترفيهية				
6.	صعوبات في الحصول على أنشطة ترفيهية مثل: مشاهدة التلفزيون ؛القراءة؛ الاسترخاء . تشغيل الكمبيوتر أوألعابه؛ استخدام الإنترنت لأغراض شخصية ؛ اللعب أو اغاني؛ والأنشطة الأخرى ، مثل حضور الفعاليات الثقافية والثقافية والترفيهية/هوايات.				
7.	ضياع الفرص للاختلاط مع الاخرين				
8.	صعوبات في استضافة الناس				
9.	صعوبات في حضور مناسبات اجتماعية				
FO2.	هل يواجه أحد من الاخوة أي من الفرص الضائعة التالية:				
	1.انخفاض الرعاية من الأب / الأم				
	2.فرص تعليم ضائعة				
	3.فرص ضائعة لنشاطات ترفيهية				
	4.فرص ضائعة لنشاطات اجتماعية				
	5.احتياجات مفقودة				
	6.لا ينطبق				

العبء المالي			
FB1.	ما هي الخدمة أو الرعاية التي تود أن تتلقاها ولكنك غير قادر على تلقيها(حدد كل ما ينطبق)		
	الخدمة	1 نعم 2 لا	أسباب عدم تلقي الخدمة: 1 عدم توفر الخدمة /قلة تقديم الخدمة 2 رداءة نوعية الخدمة 3معوقات جسدية 4 لا اعرف أين أذهب 5 عدد غير كافي من المؤسسات 6 لائحة انتظار طويلة 7 عوائق اجتماعية 8 غير مؤمن صحيا 9 عوائق مالية
	1.لاشيء		
	2.خدمات نطق /سمعية		
	3.خدمات تأهيل		
	4.تقديم مستلزمات		
	5.مساعدات اجتماعية		
	6.خدمات صحية/طبية		
	7.صحة نفسية		
	8.خدمات تعليمية		
	9.ترفيه		
	10.مواصلات		
	11.أدوات مساعدة		
	غير ذلك يرجى التحديد:		
العبء الاجتماعي والنفسي			
SC1.	هل يميز مقدمو الخدمات أو صانعو السياسات بين الاطفال ذوي الاعاقة فيما يتعلق ب:	1 نعم 2 لا	SC2.حدد الاكثر شيوعا
	1 نوع الاعاقة		
	2 عمر الطفل ذي الاعاقة		
	3 جنس الطفل ذي الاعاقة		
	4 الوضع الاجتماعي الاقتصادي		

		غير موافق بشدة	غير موافق	محايد	موافق	موافق بشدة
SC2.	أواجه صعوبه في التعامل مع طفلي ذي الاعاقة					
SC3.	تؤثر إعاقة الطفل على عدم تكوين علاقات جديدة					
SC4.	تشعرني إعاقة طفلي أني وحيد/ة ومنعزل/ة					
SC5.	أشعر بالقلق تجاه المستقبل					
SC6.	أشعر بالخجل بسبب إعاقة طفلي					
SC7.	يخلق لي الموقف السلبي للمجتمع مشاكل نفسية					
SC8.	انكسر طموحي بسبب إعاقة طفلي					
SC9.	ترهقنا الاعاقة ماليا					

SC10.	هل تلقيت تدريب أو استشارة حول كيفية التعامل مع الطفل ذي الاعاقة؟	1 نعم	2 لا

SC11.	هل تقدم أي مؤسسة أي من التالي:		منذ حدوث الاعاقة 1 نعم 2 لا	في العام السابق 1 نعم 2 لا
	1.تدريب أو توعية عن كيفية التعامل مع الطفل ذي الاعاقة			
	2.توعية عن طرق الرعاية الاساسية			
	3.التعامل مع الجانب الصحي من الرعاية			

	4.التعامل مع الادوات المساعدة		
	5.التعامل مع الجانب التعليمي		
	6.الرعاية المنزليه		
	7.أخرى		

استخدام الوقت

TU: كم تقضي من الوقت في النشاطات التالية خلال ال24 ساعة ؟

النشاط	الام/مقدم الرعاية
1.النوم	
2.الاكل والشرب	
3.اعمال المنزل	
4.تحضير الطعام	
5.شراء اللوازم	
6.اهتمام بالنفس والمسيرة المهنية	
7.الاهتمام ومساعدة افراد المنزل	
8.الاهتمام ومساعدة اطفال المنزل	
9.الاهتمام ومساعدة افراد ليسوا من المنزل	
10.العمل	
11.التعليم	
12.حضور صف (دراسة دورة..)	
13.عمل واجبات وابحاث	
14.نشاطات دينية وروحية	
15.الترفيه والرياضة	
16.التواصل الاجتماعي	
17.مشاهدة التلفزيون	
18.المشاركة في انشطة رياضة وتمارين وترفيه	
19.اتصالات /هاتف/ايميل/رسائل	
20.نشاطات اخرى غير محددة	

TUC: الوقت الذي يقضيه البالغين في رعاية أطفال البيت

نشاطات الرعاية لطفل ذي الاعاقة	**معدل ما يقضيه من الوقت كل يوم**	
	الام	**الاب**
1.الاطفال أقل من 18 عام:.....		
2.الاهتمام بالطفل كنشاط رئيسي		
3.الرعاية الجسدية		
4.النشاطات التي لها علاقة بالتعليم		
5.القراءة مع /ل الطفل		
6.التحدث مع الطفل		
7.اللعب أو ممارسة الهوايات مع الطفل		
8.الاهتمام بالطفل		
9.حضور فعاليات خاصة بالطفل		
10.غير ذلك /لطفا حدد		

TUS:	**معدل ما يقضيه من الوقت كل يوم**	
	الام	**الاب**
1.الاطفال أقل من 18 عام:.....		
2.الاهتمام بالطفل كنشاط رئيسي		
3.الرعاية الجسدية		
4.النشاطات التي لها علاقة بالتعليم		
5.القراءة مع /ل الطفل		
6.التحدث مع الطفل		
7.اللعب أو ممارسة الهوايات مع الطفل		
8.الاهتمام بالطفل		
9.حضور فعاليات خاصة بالطفل		
10.غير ذلك / يرجى التحديد		

ES1:ارجو ذكر الخدمات التى ترغب بالحصول عليها في المنزل للاطفال ذوي الاعاقة

ES2: اشياء ترغب أن تقدمها المؤسسات التي تخدم فئة الاطفال ذوي الاعاقة وتقلل العبء عليك؟

ES3: تعليقات اخرى

شكرا لك

Annex (4) FGD questions/ domains

1. How are you? How do you feel right now, how satisfied are you about your life? How your life differs from others? How this difference relates to the disability of your child? How your life changes over time as your CWD grows up? What about the gender element? Which role does it play in changing your life?
2. Please tell me about your typical day, how it looks like, what you do from the sunrise to sunset? How that differ from caregivers who don't have CWDs? How do you perceive your life in that pattern? How much care of the CWD constitute a burden on you? Who helps you (family, extended family, residential care)
3. What sorts of support (from government/ NGOs/ religious organizations) you receive in relation to the disability of your child? What are the main challenges that your family faces in providing support to your child? What are the pressing unmet needs (financial, health, assistive devices, etc.)?
4. How much the following constitute a burden on you? Self-care and hygiene, education, transportation, health care, socialization, transportation, costs of care, etc.
5. In an ideal condition, who should provide support to you but unfortunately, didn't? what kind of support you are badly in need for? Discuss all the components.
6. How much the community is an inclusive one? Reflect on health, education, recreation, xxx how the community interacts and socializes with you? Tell me about discrimination? Support your argument with stories and examples. Tell me about your socializations and friendship.
7. What sorts of changes/ complimentary support or services would make life better for your child and for your family?
8. What kind of training you and your family need to be better able to support the CWD?
9. What are the forgone opportunities for you are your family that are attributed to disability (education, work, socialization, recreation, depriving other family members from the care)?
10. If you would like to send a letter to a responsive policy maker, what would you like to focus on to address some of the challenges facing caregivers?

Annex (5) IDI with siblings

1. Please tell us about your family. What sort of disability does your sibling have? What care do different family members?
2. provide? What do you do? What do you like doing? What do you find more challenging?
3. What sorts of support does your sibling get? What are the main challenges that your family faces in providing support? to your sibling?
4. Are you or other family members treated the same or differently to children/ families who do not have a family member with a disability? If differently, how does this make you feel?
5. Do you have other friends in the same situation as you with whom you can discuss your experiences/ concerns/ etc.?
6. What sorts of changes/ additional support or services would make life better for your sibling and for your family?

Annex (6): KII Questions.

1. Can you tell us about your organization, type of services it provides, your programs for serving CWDs? Probe for services for caregivers.
2. Tell me about your beneficiaries, targets, how you approach them, size of the program.
3. Tell me about the feedback you are getting about your services, How do children and their families find your organization's services?
4. Let us discuss in detail the kind of services you provide and the support you provide to the family with CWD. Probe for Education, health, rehabilitation, assistive devices, counseling, psychosocial support, cash, food aid, disposables, transportation, fees,
5. What are the challenges facing families seeking these services? Costs, transportation, time
6. Who usually seek these services more? Why? Who is unlikely to seek these services? Why? Besides the CWD, what is being specifically provided to the caregiver of CWDs?
7. Tell me about the burden of having CWD? Who is more affected and how? How families cope, who is more able to cope and who is not?
8. I am interested to know more about specific programs to support mothers of CWDS, how much these are available, outreach programs, residential care, how much these are needed and what are the challenges for launching such programs?
9. One challenge faced by families of CWDs is stigma? how this can be reduced, what you do to reduce it?
10. How we can support families of CWDs? Mothers, father, sisters, brothers

Annex (7) List of Key informants interviewed

No	Organization	Name
1.	Ministry of Education and Higher Education	Mr. Khaled Fedda
2.	UNRWA	Dr. Zohir Al Katib
3.	UNRWA	Mr. Mohammad Farahat
4.	Ministry of Health	Dr. Ayman Alhalabi
5.	Ministry of Social Development	Dr.Ghassan Felfel
6.	Atfaluna Society for Deaf Children	Naeem Khabaja
7.	Right to Live (for children with Down syndrome and autism)	Nihal AlAsshi
8.	Future Palestine	Ahmad Khashief
9.	Physically Disabled Association-	Sameer Abu Jaiab
10.	Advocacy groups for disability	Haneen Reziq Alsammak
11.	Gaza psychology health center	Dr. Sami Oweda

Annex (8) An official letter of approval from Helsinki Committee in the Gaza Strip

المجلس الفلسطيني للبحث الصحي

Palestinian Health Research Council

تعزيز النظام الصحي الفلسطيني من خلال مأسسة استخدام المعلومات البحثية في صنع القرار

Developing the Palestinian health system through institutionalizing the use of information in decision making

Helsinki Committee

For Ethical Approval

Date: 04/06/2018 **Number:** PHRC/HC/397/18

Name: Mariam A. Mohanna الاسم:

We would like to inform you that the committee had discussed the proposal of your study about: نفيدكم علماً بأن اللجنة قد ناقشت مقترح دراستكم حول:

Quality of Life among Caregivers of Children with Disabilities in the Gaza Strip

The committee has decided to approve the above mentioned research. Approval number PHRC/HC/397/18 in its meeting on 04/06/2018 و قد قررت الموافقة على البحث المذكور عاليه بالرقم والتاريخ المذكوران عاليه

Signature

Member **Member**

Chairman

Genral Conditions:-

1. Valid for 2 years from the date of approval.
2. It is necessary to notify the committee of any change in the approved study protocol.
3. The committee appreciates receiving a copy of your final research when completed.

Specific Conditions:-

E-Mail:pal.phrc@gmail.com

Annex (9) Administrative Approvals from The National Society for Rehabilitation

الجمعية الوطنية لتأهيل المعوقين
بقطاع غزة

The National Society For Rehabilitation
Gaza Strip

غزة – الرمال – شارع سعيد العاص ص.ب: ١٢٩٨ ، تليفون : ٢٨٦١٢٦٦ / ٢٨٦٦٤٢٩-٠٨ ، فاكس : ٢٨٢١٠٨٢-٠٨.
Gaza - El Remal - Said El As St./P.O.Box: 1298, Tel.: 08-2861266/2866429 , Fax: 08-2821082
بريد الكتروني: E-mail: ncbrgaza@palnet.com الموقع الالكتروني: www.gnsr.org

إقـــرار وتعهـــد

أقر انا الموقعة أدناه..... هوية رقم 931681985.....

بأنني قد حصلت على معلومات خاصة بالأشخاص ذوي الإعاقة من الجمعية الوطنية لتأهيل المعوقين بواسطة برنامج الجمعية الخاص بقاعدة البيانات لذوي الإعاقة من عمر عام وحتى 17 عام (جميع المناطق وجميع أنواع الإعاقة) بهدف البحث العلمي، وأنني اتعهد بعدم استخدام هذه المعلومات لأي غرض أخر أو مشاركتها مع أي جهة كانت، وأتحمل كامل المسئولية القانونية كاملة في حال خالفت هذا التعهد.

وهذا إقرار مني بذلك،،،،

الاسم..... رقم الجوال: ....0599219051..

رقم الهوية.....931681985.....

العنوان كاملا .....

التوقيع .....

التاريخ.....21/11/2019.....

Annex (10) Administrative Approval from Medical relief association

Al-Quds University
Jerusalem
School of Public Health

جامعة القدس
القدس
كلية الصحة العامة

التاريخ 2019/1/23

حضرة / الأستاذ جمال الرزي المحترم
المدير التنفيذي للجمعية الوطنية للتأهيل
تحية طيبة وبعد،،،

الموضوع:مساعدة الطالبة مريم كلاب

نشكر لكم دعمكم الدائم لمسيرة العلم والتعليم وخصوصاً دعم كلية الصحة العامة وطلابها، ونود أعلامكم بأن الطالبة المذكورة أعلاه تقوم بعمل بحث كمتطلب للحصول على درجة الماجستير في الصحة العامة–مسار الإدارة الصحية بعنوان:

Quality of Life among Caregivers of Children with Disabilities in the Gaza Strip

وعليه نرجو من سيادتكم التكرم بالموافقة على تسهيل مهمة الطالبة في إنجاز هذا البحث وتوفير البيانات اللازمة لها وتسهيل تعبئتها من خلال قاعدة البيانات المسجلة لديكم في جمعيتكم الموقرة.

شاكرين لكم حسن تعاونكم ودعمكم للمسيرة التعليمية،،،
و اقبلوا فائق التحية و الاحترام،،،

د. بسام أبو حمله
منسق عام برامج الصحة العامة
جامعة القدس–فرع غزة

نسخة: الملف

التاريخ: 2018/12/22

Al-Quds University
Jerusalem
School of Public Health

جامعة القدس
القدس
كلية الصحة العامة

التاريخ 2019/1/23

حضرة / الدكتور عائد ياغي المحترم
مدير جمعية الإغاثة الطبية
تحية طيبة وبعد،،،

الموضوع:مساعدة الطالبة مريم كلاب

نشكر لكم دعمكم الدائم لمسيرة العلم والتعليم وخصوصاً دعم كلية الصحة العامة وطلابها، ونود أعلامكم بأن الطالبة المذكورة أعلاه تقوم بعمل بحث كمتطلب للحصول على درجة الماجستير في الصحة العامة–مسار الإدارة الصحية بعنوان:

Quality of Life among Caregivers of Children with Disabilities in the Gaza Strip

وعليه نرجو من سيادتكم التكرم بالموافقة على تسهيل مهمة الطالبة في إنجاز هذا البحث وتوفير البيانات اللازمة لها وتسهيل تعبئتها من خلال قاعدة البيانات المسجلة لديكم في جمعيتكم الموقرة.

شاكرين لكم حسن تعاونكم ودعمكم للمسيرة التعليمية،،،
و اقبلوا فائق التحية و الاحترام،،،

د. بسام أبو حمد
منسق عام برامج الصحة العامة
جامعة القدس–فرع غزة

نسخة: الملف

Annex (11) List of arbitrators

No	Name
1.	Dr. Yehia Abed
2.	Dr. Bassam Zaqout
3.	Khaled Fedda
4.	Moustafa Abed
5.	Soha Abu Ghazza
6.	Ahmad Kashief
7.	Ghassan Felfel
8.	Haneen Rezeq Alsammak

Annex (12) Budget

Item	**Units used**	**Cost in $**
Personnel		
Data collectors	400* 5 $ (per questionnaire)	2250
Data analysis Biostatistician	Package	0
Local Transportation Costs		
Domestic Travel of research Team	Package	300
Participant Travel cost for Focused Group meetings	80 participants * 5 $	400
Stationaries and printing		
Questionnaire	Package	500
Other costs		
Training for data collection	2 days	200
Refreshment cost	Package	300
Minor Equipment, Tap recorder	1 tap * 100$ (per tap)	100
Communications	Package	200
Total Project Costs	**45**	4250$